PERCEPTIONS OF PALLIATIVE NURSING

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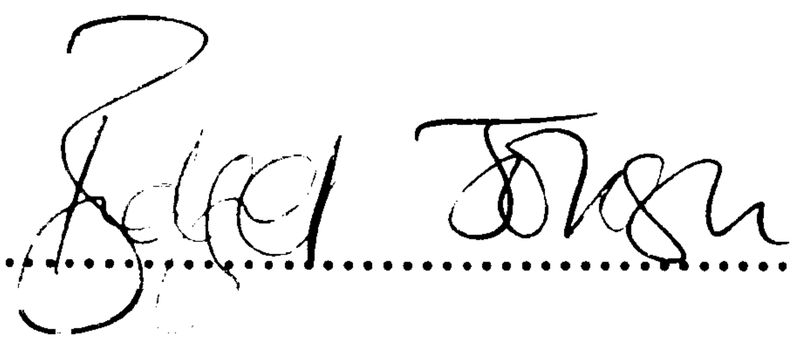
DATE: 29/5/02 **SIGNATURE:** 

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Abstract

Perceptions of palliative nursing

This thesis describes a three-year study which explored the lived experiences of nurses delivering palliative care, and dying patients receiving palliative care. The aim of the study was to examine the perceptions of patients and nurses regarding palliative care, and in particular, how they described a good palliative care nurse.

The study design employed methodological triangulation, with a phenomenological, theoretical, framework underpinning the study. Data were collected via in-depth interviews and repertory grids, with a sample of 22 registered nurses, and 22 dying patients. The sample of nurses all completed both interviews, whereas, 22 patients took part in the in-depth interviews, and nine patients completed the repertory grids.

Data were analysed using thematic content analysis within Colaizzi's (1978) framework (in-depth interviews) and the repertory grid software package, FLEXIGRID, and descriptive and inferential statistics (repertory grids). A pilot study was conducted and ethical committee permission granted, before commencing, the main study.

The study generated interesting and significant findings. The lived experience of dying patients was characterised by maintaining their independence, and remaining in control, even in the latter stages of their illness, as well as wanting to feel safe and secure and being supported by their family and the nurses who were looking after them. Patients wanted palliative nurses to be there for them, by spending time with them, provide comfort, by meeting their needs, and for nurses to listen to their fears.

The lived experience of palliative nurses was characterised by effective and ineffective interpersonal communication, the building of therapeutic relationships with dying patients, attempting to control pain and distressing symptoms, endeavouring to work as an effective multi-disciplinary team with their colleagues, and developing knowledge and experience in palliative care.

The two most important characteristics of a good palliative nurse, as far as both patients, and nurses, were concerned, was to be interpersonally skilled, in particular the ability to be 'willing to listen', as well as, the need for the nurse to possess personal, humane qualities such as kindness, warmth, compassion and genuineness.

Nurses, in particular, perceived that a good nurse should have knowledge, experience and keep up to date via professional development, in addition to, being skilled in controlling pain and distressing symptoms.

No patients identified being skilled in pain and symptom control as a requirement of a good palliative nurse. They did, however, indicate that a good palliative nurse should be tuned into their needs, know about their illness, and get to know them as a person by spending time with them.

This study has significant implications for nursing practice, in particular the recruitment of palliative care nurses, nursing education, specifically, the curriculum for specialist palliative care education and nursing research. Despite problems with sample attrition, dying patients proved to be reliable and valuable informants.

Chapter One Introduction

1.0 Introduction

The ideas for this thesis were first generated when I was studying for a full-time post- registration degree in nursing. The degree allowed me to reflect and ponder on the nature of nursing and the unique contribution of nurses to health care. In my final year dissertation, I chose to explore the educational needs of student nurses regarding death and dying (Irvine 1991). At this time, I had my first experience of working in a hospice after a previous clinical background in acute oncology. These two experiences introduced me to the world of palliative care and to consider the experiences of nurses and patients in this field.

My experience with nurses and patients in specialist palliative care enabled me to believe that these were unique groups of people. I considered that the relationships that nurses had with their patients were different from other specialities. Nurses and patients formed deep friendships without stepping over the professional/patient boundary. I also discovered that patients had strong views on what they wanted from their care and from their carers.

Furthermore, I have always been interested in what it is that nurses do and what makes nursing different and special. I have been inspired by the seminal work of Benner (1984), Lawler (1991), Morse and Johnson (1991) and Taylor (1994): among others. I therefore considered that many nurses are not able to articulate what it is that they contribute to the care of the patient and what they do that makes a difference to patient care.

Specialist palliative care has changed dramatically since I first entered the speciality 10 years ago. It is now much more medicalised, with advances in symptom control, palliative treatments and career doctors. I have a view that, as specialist palliative care has improved and as more health care practitioners and academics become interested in this field, that the role of the nurse is being eroded and devalued. Patients who receive palliative nursing care do not, however, hold the view of a 'medicalised death'. I can remember speaking to a patient in a hospice in England who was able to explain, unprompted, what the nurse involved in her care had done

for her. She was also able to differentiate between untrained and trained staff and she recognised the contribution that palliative nursing care had made to her wellbeing and quality of life.

Few researchers or practitioners ask patients for their views on palliative nursing care. There are often assumptions made about what patients want from their care, both in terms of symptom control and psychosocial care. There is also a large body of evidence regarding the differences between professionals' and patients' views of care (Seers 1987; Camp 1988; Holmes and Eburn 1989; Slevin, Stubbs, Plant, Wilson, Gregory, Armes and Downer 1990; Higginson and McCarthy 1993; Jandelli 1995). This evidence led me to decide to differentiate between nurses' and patients' views about their care.

1.1 Scope of the thesis

Essentially, what I wanted to achieve from this study was to explore the phenomenon of palliative nursing care and to investigate the lived experience of the palliative nurse. I proposed the research in the hope of recognising the valuable contribution of nursing to the care of dying patients and to raise possibilities for more effective nursing practice. I also wanted to add to the body of knowledge in palliative nursing care as well as providing information for planning educational programmes.

The goal of the research was therefore to investigate the role of the nurse in palliative as perceived by both the nurses themselves and their dying patients.

Chapter 2 Literature Review

2.0 Introduction

A literature review entails being able to locate and summarise the findings of research on a given topic, as well as, setting the research problem within its context (Abbott 1993). In addition, a literature review should provide a critical summary of the 'state of the art' on a research problem (Polit and Hungler 1999). Palliative nursing, as a topic, has historically been under-researched which made constructing the literature review more difficult, and hence the choice of framework for the review (section 2.0.1). Although, researching dying patients and nurses is not without its pitfalls, there are three main criteria that indicate why research in this area is worthwhile. These criteria consist of a moral/philosophical, a political, and an academic, evidence based argument.

Firstly, the moral or philosophical argument is that by ignoring the views of dying patients, their autonomy is being usurped. The paternalistic health care world appears to believe that listening to the stories of dying patients may somehow harm them. Furthermore, the increase in accounts by patients suffering from life threatening diseases (Diamond 1998; Picardie 1998) indicates the importance patients attribute to telling the story of their illness. Both the above writers were journalists who wrote columns about their illnesses in national newspapers. They describe the volume of letters they received from readers who were dying, and the therapeutic benefit they and others received from voicing their opinions on this 'taboo' subject.

Secondly, the political argument concerns the number of government and patient association reports that point to a move towards a more patient-led health service. Patients' opinions are now being sought and valued on a whole range of health matters, including cancer and palliative care (Scottish Executive 2001).

Thirdly, the academic or evidenced-based argument for carrying out research with dying patients, and in particular, this study, is discussed in detail in the literature review. Suffice to say, that research asking dying patients for their opinions of their

care in general, and in particular, their nursing care is insufficient and warrants further investigation.

2.0.1 Search parameters

The literature review was conducted using the criteria outlined for carrying out a systematic review (Hearn, Feuer, Higginson, Sheldon 1999). The search for research evidence was undertaken using the following databases: CINAHL, Index to Theses of Great Britain and Ireland, Dissertation abstracts, Medline and PsycLIT. Table 1 outlines the key words and databases used with each of the topic areas. CINAHL was used, as it is the primary database for nursing literature in both the U.K. and the rest of the world. Medline was used to supplement the CINAHL search, as Medline covers a wider range of source material than CINAHL, and uses different indexing criteria. It also includes some of the palliative care journals that CINAHL omits such as Omega. In addition, Hearn et al (1999) indicate that, for a comprehensive search to be carried out, more than one database should be accessed. Index to Theses of Great Britain and Ireland and the American equivalent Dissertation abstracts were used in order to access British and International PhD theses related to the search criteria. PsycLIT as the primary psychology database, was used as to incorporate a comprehensive search for literature related to the repertory grids.

The failure of electronic databases to find all the relevant studies on the topic of palliative care has been identified (Hearn et al 1999). Therefore, the reference lists of papers that fitted the inclusion criteria were examined as they were retrieved and further articles identified in this way. In addition, a hand search for the years 1994-1999 was conducted, in order to ensure that essential literature was not omitted. The following journals were used for hand searching: Cancer Nursing, Journal of Advanced Nursing, International Journal of Palliative Nursing, International Journal of Nursing Studies, Journal of Cancer Care, Journal of Cancer Nursing, Journal of Palliative Care, Oncology Nursing Forum and Palliative Medicine. In addition to using the databases described above, key PhD theses were sought using the RCN Steinberg Collection, personal contacts, conference abstracts and contacting key university departments. Relevant theses were then accessed via inter-library loan from the British Library Document Supply Centre.

Inclusion/ Exclusion criteria

Parameters or inclusion criteria were developed to set limits to the scope of the review, and to provide a systematic review, without yielding a large amount of irrelevant papers.

Firstly, it was decided that studies should be in English only, in order to avoid the problems related to requiring translation of texts. In addition, studies were only included if they were conducted in Europe, North America, or Australasia. Studies from other countries were omitted, as the practice of palliative care outside the western world differs too much from the U.K. practice. The literature search was limited to studies from the years 1989-2000. This 11-year parameter was placed on the literature in order to avoid outdated articles and to avoid generating too large a volume of literature which may have made it harder to critique and appraise studies. Seminal or classic studies pre 1989 were however included when that literature was considered 'state of the art' in a particular topic or field.

Articles were excluded if they consisted of personal opinion or individual case histories. Studies about cancer rather than palliative nursing were only included if the role of the nurse in palliative care was specifically mentioned. Pilot studies were not included. As pilot studies are precursors to a main study, they are not as useful as main studies in terms of application and transferability. Articles that could not be accessed directly by the researcher, or via inter library loan from the British Library, were also excluded.

Although, there is no validated 'gold standard' for the true methodological quality of a study, whether it is qualitative or quantitative in research design, (Oxman 1995) the aim in choosing research was to identify studies, which by virtue of their design and quality of conduct, analysis and reporting were the least biased and most reliable. For these reasons, articles were omitted if they did not give any or enough information on the methodology used, sample size, data collection and data analysis.

Keywords for literature searching were identified from the study aims and from articles accessed in the early stages of the review and are displayed in Table 1.

Table 1 Databases used for literature search according to topic and keywords

TOPIC	KEYWORDS	DATABASES
Role of the nurse	Nurse-patient relationship, nursing role and palliative care and hospice care and terminal care and cancer.	CINAHL, Medline, Index to Theses of Great Britain and Ireland Dissertation abstracts
Caring	Caring theorists, caring research, comfort, caring	CINAHL, Medline
Patients and nurses perceptions of palliative care	Perceptions and palliative care and hospice care Interviews and dying patients.	CINAHL, Medline, Index to Theses of Great Britain and Ireland Dissertation abstracts
Good death	Good Death, Death and Dying-psychosocial factors	CINAHL, Medline
Dying experience	Process of dying, dying experience, attitudes to death, terminal care and palliative care-psychosocial factors	CINAHL, Medline, PsycLIT
Theories of death and dying	Psychological theory, death-psychosocial factors, dying theory	CINAHL, Medline, PsycLIT

The results of the literature search were that a total of 958 documents were identified from the keyword search. Of these 200 were retrieved and analysed. A total of 93 articles appeared to be relevant to the research questions and aims of the study. These studies formed the basis of this review.

2.0.2 Framework for the literature review

It has been suggested that a literature review be conceptualised within a theoretical framework, which is usually structured around the research questions (Marshall and Rossman 1995). The conceptual framework, therefore, provides not only the framework for the critical review of the literature, but also the research as a whole, indicating the researcher's assumptions about the research problem. The framework also demonstrates how the researcher sees the world in terms of the subject matter and how they see the research questions fitting into the framework.

The conceptual framework for organising the literature review for this study was developed using the research questions (section 2.7) and the World Health Organisation (1990) definition of palliative care. This framework was chosen as it best encapsulates both the philosophy of the study and the philosophy of palliative care as a whole.

The World Health Organisation Expert Committee on Cancer Pain Relief and Active Supportive Care (1990) defined palliative care as:

> "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families…….. Palliative care:
>
> - Affirms life and regards dying as a normal process;
> - Neither hastens nor postpones death;
> - Provides relief from pain and other distressing symptoms;
> - Integrates the psychological and spiritual aspects of patient care;
> - Offers a support system to help patients live as actively as possible until death;
> - Offers a support system to help the family cope during the patient's illness and in their own bereavement" (World Health Organisation 1990 p. 11).

The title categories used to report the literature review are therefore:

- Palliative nursing care – patients' perspective;
- Palliative nursing care – nurses' perspective;
- Differences between patients' and nurses' perspectives of palliative nursing care;
- Characteristics of caring (nurse and patient views);
- Conceptualisation of the dying experience.

Table 2 indicates how the literature review title categories relate to the research questions and the WHO definition.

Table 2 Development of categories for the theoretical framework of the literature review and their relationship to the research questions and WHO definition

CONCEPT CATEGORY AND SUB-CATEGORIES (ITALICS)	RESEARCH QUESTION	WHO DEFINITION
The meaning of good care for the dying patient- good death	What is palliative nursing care from the patient's perspective?	Affirms life and regards dying as a normal process Neither hastens nor postpones death
Patients' perceptions of palliative nursing care *Patients' views of their care* *Patients' experiences of hospice* *The lived experience of terminal illness* *Patients' views of pain and symptom control* *Patients' views of their psychosocial care*	What is palliative nursing care from the patient's perspective?	Provides relief from pain and other distressing symptoms Integrates the psychological and spiritual aspects of patient care Offers a support system to help patients live as actively as possible until death Offers a support system to help the family cope during the patient's illness and in their own bereavement
Nurses' perceptions of palliative care *Expert/good nurse in palliative care* *Supportive role of the nurse* *The experience of being a hospice nurse* *Impact of death and dying on the palliative care nurse* *The role of the nurse in providing psychological and spiritual care* *The role of the nurse in providing pain and symptom control*	What is palliative nursing care from the nurse's perspective?	Provides relief from pain and other distressing symptoms Integrates the psychological and spiritual aspects of patient care
Comparing patients' and nurses' perceptions of the role of the nurse in palliative care	Are there differences between patients' and nurses' perceptions as to what constitutes good palliative nursing care?	
Caring and nursing	What do dying patients identify as characteristics of caring? What do nurses caring for dying patients identify as characteristics of caring?	
Conceptualisation of the dying experience	What is palliative nursing care from the patient's perspective? What is palliative nursing care from the nurse's perspective?	

2.1 The meaning of good care for the dying patient- good death

Families or health professionals who witness the death of a person with a terminal illness often categorise the death as 'good' or 'bad', with a 'good death' seen as one which involved a high standard of care. The quality of palliative care both preceding and at the time of death is influenced by socio-cultural, environmental, political, economic and institutional factors (Quint Benoliel 1987/1988), as well as family expectations and experiences, and patients' and health care professionals' perspectives of care.

Payne, Langley-Evans and Hillier (1996) indicated that the notion of a 'good death' can be interpreted in two ways: it can relate to a fixed moment in time, (the death event)- or it can refer to the dying process, (the complex set of relations and preparations, which take place over time). For the purposes of this thesis, the author uses the latter definition to determine how both nurses and patients perceive good care for the dying patient.

Few authors have explored the notion of a 'good death' or what 'effective care' means to the dying patient. The exceptions tend to view a 'good death' as incorporating how the individual copes with dying in a social or psychological way. For instance, the notion of social support was first explored as a component of coping with dying by Weisman (1979). He asserted that a 'good death' or 'appropriate death', as he preferred to call it, comprised three major categories- 'disease', 'personality' and 'social context'. He also proposed that self-regard was an important concept in a 'good death'. De Raeve (1996a) supported this issue by asserting that self-respect was a factor in maintaining the patient's dignity and integrity at the end of life. Weisman put forward an argument that how patients cope is a major factor in how they perceive the process of dying. He indicated that this depended on the social context, including the role of supportive others.

On the other hand, Stephen, (1991-1992) in his critique of Weisman's work further considered the concept of an 'appropriate death' to be a clustering of three components- 'consistency in functioning', 'idiosyncratic views of appropriate' and 'features which contribute towards a better death'. He argued that 'appropriate death' should not be seen as synonymous with 'good coping'. He perceived that

coping is only one component of an appropriate death. He further acknowledged that the term 'appropriate' or 'good death' should really be 'appropriate dying', as it refers to the process of dying and not the actual death. Stephen maintained that patients themselves should be asked to generate data on the appropriateness of dying, something that few studies have attempted to do, the exceptions are (Kellehear 1990; Payne, et al 1996).

This notion of a socio-cultural view of the process of a good death was further identified in an Australian study by Kellehear (1990) who examined the experiences of cancer patients in the last year of their lives. Using a descriptive research design, Kellehear interviewed 100 patients dying of cancer. The sample was drawn from oncology and haematology outpatients at one Australian hospital, 10 of whom were also hospice patients. Structured interviews were chosen as the method to collect data, which was analysed using inferential statistics and content analysis for the open-ended questions. The findings identified the key features of a 'good death' as 'the social life of the dying person', 'the creation of open awareness', 'the social adjustment to and personal preparation for death', 'the public preparations such as arrangements relating to work' and 'the final farewells'. Kellehear therefore argued that a good death is one that involves a great deal of social interaction.

There are methodological limitations to the study. An attempt was made to quantify a phenomenon that may have been more appropriately analysed qualitatively. Multiple interviews with a smaller sample size may have produced a fuller picture of the dying experience. Kellehear maintained that the sample was statistically representative; but he also notes that the sample could not be completely randomised as only patients who were not in denial and were aware that their prognosis was one year or less were approached to participate in the study.

On the other hand, Hunt (1992) identified the concept of a 'good death' as a physical process. The purpose of her ethnographic study, using an extended case study approach, was to explore the perceptions and expectations of nurses of a 'good death' in a symptom control team with those of their patients and relatives. The study was conducted with a population of five community symptom control or Macmillan nurses and 54 cancer patients. All five nurses in a hospital symptom control team

were included in the study. A convenience sample of patients on the nurses' caseload was recruited to the study with the permission of their hospital doctors and general practitioners. Data were collected using audio recordings of conversations between the nurses and their patients as part of the nurses' normal work. The nurses carried unobtrusive audio-recorders in their bags, and the researcher was not present at the time of the interviews. The ethical issues arising from this type of encounter were not discussed.

The findings indicated that the nurses perceived a 'good death' as incorporating control of physical symptoms and patients and relatives openly accepting the cancer diagnosis and prognosis, as well as the presentation of hope and the desire to live, the ability to keep mobile and fight back, enjoyment of life and a peaceful death at home.

The study has some major methodological flaws which detract from what could have been an important addition to the field of palliative nursing. The patients and nurses were not interviewed separately, making it difficult to draw comparisons between them. Likewise, the patients were not asked specific questions; instead their conversations with the nurses delivering their care were recorded. Although participation or 'covert' observations and informal interviews are a hallmark of the ethnographical approach, (Atkinson and Hammersley 1998), there appear to be profound ethical implications arising from the study. The 'scripts for dying' that emerged from the data were, therefore, determined by the nurses and not the patients, and were composed of the nurses' philosophy about caring for dying patients.

Similarly, in a small-scale study exploring nurses' perceptions of a 'good death', Wilkes (1993) elicited the views of a convenience sample of 16 nurses undertaking courses at the researcher's university. The themes of a 'good death' that emerged were 'painless', 'patient acceptance', 'family present', 'chosen environment', 'mental capacity maintained', 'in-sleep' and 'no distressing symptoms'. The majority of nurses (n=10) perceived that a 'good death' was a pain-free death.

Despite the fact that the physical effects of dying profoundly affect bodily function and invariably the individual's quality of life, dying usually involves facing the death

of one's self which involves psychological, social, spiritual and existential elements. However, this research ignores the non-physical elements in the process of dying.

McNamara, Waddell and Colvin (1994) further extended the exploration of the issue of good dying. They used an ethnographic research design to collect data from an in-patient hospice in Western Australia over an eight-week period. A total of 22 hospice nurses and community nurses attached to the hospice (home care sisters) were interviewed in order to ascertain their views of good palliative care. Data were collected using participant observation in both settings. The findings indicated that good deaths from a nursing standpoint were characterised by excellent standards of care and adequate symptom control. In contrast, 'bad deaths' were perceived to be a drain on resources and a consequence of patient and family failing to internalise the hospice philosophy. This point is interesting: 'bad deaths' in reality, or from the patients' or relatives' perspective may have had more to do with bad care or poor pain and symptom control.

Following on from the work of McNamara et al (1994), Payne et al (1996), Low and Payne (1996), and Langley-Evans and Payne (1997) conducted an ethnographic investigation in a palliative day care unit in the south of England over a seven week period. The study aimed to elicit the views of a convenience sample of 18 patients and 20 health care professionals regarding a 'good death'. The study extended the concept of a 'good death' from the previous studies by including a spiritual and psychological component to the quality of the process of dying. Data were collected using semi-structured interviews and participant observation and analysed using content analysis. The findings indicate that the patients perceived a good death to be 'dying in one's sleep', 'dying quietly and suddenly', being 'not afraid', having 'religious beliefs' and being 'pain free'. Staff perceived a good death to be 'no sign of physical pain', 'family acceptance', 'a peaceful death', 'location of death as patients' choice', 'presence of loved ones' and the 'staff are able to make the dying process more comfortable'. There were high levels of agreement among the different members of the staff teams on the characteristics of a 'good death'. For ethical and sensitivity reasons, patients were not asked about their perceptions of a 'bad death'

A weakness of the study was the fact that it was conducted with a convenience sample of patients, all of whom had already mentioned the process of dying. The high levels of agreement amongst the different staff disciplines regarding a 'good death' reflect the shared narratives among hospice professionals (Stephen 1991-1992; Wilkes 1993; McNamara et al 1994).

2.1.1 Summary

The lack of consensus between health care professionals and patients on what constitutes a good death and the lack of studies on patients' views of a good death make it difficult to draw conclusions in this area. Nevertheless, the current state of knowledge regarding good death and good dying shows that health care professionals perceive a good death to be a physical and psychological process affection a persons' quality of life. A high standard of care is necessary to achieve a good death, particularly in the areas of pain and symptom control. Indeed, a pervasive element amongst health care professionals and patients was for a 'pain free death'. Health care professionals also perceived that a good death involved a positive coping strategy and acceptance on the part of the patient. This issue is understandable, yet suggests that professionals are not taking into account the individuals' personal and individual approach to dying. Patients, on the other hand, perceived a good death as one in which they had prepared themselves psychologically, such as saying final farewells. Good dying for them also involved being 'pain free' and 'not afraid'.

However, none of these studies, and therefore current knowledge in this area, incorporated a multi-dimensional perspective (psychological, social, spiritual, physical and existential) into the process of dying, instead focussing on one or two of these aspects. Dying as a process however, involves all the above aspects and to omit one or more elements is to ignore the holistic experience. This narrow perspective may be due to methodological flaws in the studies.

The real issues are therefore that a good death and the process of dying are rarely explained and explored. The studies are, on the whole, articulated from a professional viewpoint, ignoring the views of dying patients. In addition, the studies are predominately small-scale with ethical weaknesses. The ethical weaknesses are predominately in the areas of justice and autonomy. By using convenience samples

and informants who have already articulated a view regarding the process of dying, there is a danger that the patient's voice is not acknowledged. Moreover, the lack of acknowledgement of the patients' viewpoint seems to imply that researchers are afraid of upsetting dying patients by asking them about their experiences, at a potentially distressing time (for a detailed explanation of this issue see Cartwright and Seale 1990). This fear of talking about death with dying patients appears to be an issue for professionals rather than the patients themselves. This is evidenced by the number of patients writing accounts of their dying in the media and popular literature. It therefore follows that an academic exploration of patients' views of their death and dying is worthwhile and timely. An appropriate area to follow in an exploration of the literature would appear to be an exploration of patients' views of their nursing care.

2.2 Patients' perceptions of palliative nursing care

This section explores the literature related to patients' views of their nursing care, patients' experiences of hospices, the lived experience of terminal illness, Patients' views of pain and symptom control, psychosocial problems and needs of patients.

2.2.1 Patients' views of their palliative nursing care

There is a dearth of literature related to how dying patients perceive their care. This may be because health care professionals working with the dying appear to take a paternalistic rather than an autonomous viewpoint, by considering that professionals know what is best for the dying patient. Moreover, researchers often prefer instead to ask family members about the dying person's experience (see section 2.2.2 and section 2.2.6).

The literature search uncovered only one study (Arblaster, Brooks, Hudson and Petty 1990). This lack of literature reflects the issues discussed above (section 2.1), that dying patients' opinions regarding their care are rarely sought.

The Australian study used a descriptive research design (Arblaster et al 1990). The purpose of the study was to explore what nursing behaviours were considered by terminally ill patients to be helpful. Data were collected by a 70 item Q-sort technique from a convenience sample of 40 terminally ill patients being cared for at

home. Data were sorted into nine categories and analysed using principal component factor analysis.

The findings indicated that the most favoured statement was: 'I would like the nurses to help me to stay at home for as long as possible'. The least favoured statement was: 'I would like the nurse to talk to me about death and dying'. This finding is somewhat surprising, given the volume of research suggesting that dying patients do want to talk with nurses (Seale 1991a; May 1995; Montazeri, Milroy, Macbeth, McEwen and Gillis 1996; Chan and Woodruff 1997; Graydon, Galloway, Palmer-Wickham, Harrison, Rich-van der Bij, West, Burlein-Hall and Evans-Boyden 1997). Overall ranking of the statements indicated that patients who are terminally ill prefer nursing behaviours which are responsive to their individual needs. The fact that it was conducted in one setting is a limitation of the study. The study may also have been enhanced by a longitudinal research design, interviewing dying patients at different points in their journey. The study also did not explore dying patients' perceptions of hospice care as such, or elicit patients' views of different care settings. It therefore seems pertinent to explore the literature related to patients' experiences of hospice care.

2.2.2 Patients' experiences of hospices

A small number of studies have explored patients' perceptions of hospice care (McDonnell 1989; Raudonis 1993; Field, Douglas, Jagger and Dand 1995; Rasmussen and Sandman 1998). Moreover, only Raudonis (1993) and Rasmussen and Sandman (1998) explicitly sought the views of patients regarding their nursing care in hospices. Other studies have explored the notion of hospice care from the perspective of families caring for dying patients, (Hull 1991; Seale 1991b; Seale and Kelly 1997) but were not included in this review, as they did not fulfil the search criteria (see section 2.3). This lack of evidence regarding patients' perceptions of their hospice nursing care may be because patients find it difficult to separate their nursing care form other aspects of their care or because they have not been specifically asked about their nursing care. Yet, this does seen surprising when it could be argued that nursing care is an essential aspect of hospice care and that nurses have been at the forefront of the care of dying for a number of years. Indeed,

the founder of the hospice movement Dame Cecily Saunders was herself a nurse originally.

In a small-scale descriptive study undertaken in Dublin, McDonnell (1989) explored the views of patients prior to their admission to a hospice. The purpose of the study was to identify patients' needs, expectations, awareness of their illness, and awareness of the hospice. Data were collected using two informal interviews from 50 patients (31 completed the second interview).

The findings indicated that half the patients were aware that they were dying and understood that they were going to a hospice. Most of the patients did not express any fears of the hospice. Most hoped for physical relief from their illness, and comfort. In the second interviews, most patients praised their care. They perceived that they felt 'peaceful', 'calm' and 'comfortable'.

There are many limitations with the study, mainly in relation to the research design. The researcher does not indicate what type of qualitative research was used. There is, therefore, no theoretical underpinning to the work. Likewise, no indication is given as to how data analysis was carried out. In addition, the study was carried out in one hospice and is, therefore, not generalisable. Moreover, the patients were asked for their opinions of their care while still in-patients, which may have made it difficult for them to criticise their care (Astedt-Kurki and Haggman-Laitila 1992; Bond and Thomas 1992; Thomas and Bond 1996; Fakhoury 1998).

Raudonis (1993) carried out a more detailed exploration of patients' experiences of their hospice care. A naturalistic field study was used to explore the patients' perspective of the nature, meaning and impact of empathic relationships with hospice nurses in Oregon, U.S.A. In-depth interviews were used to generate data from 14 terminally ill hospice patients. Data were analysed using Ethnograph.

The findings demonstrated that 10 of the 14 terminally ill patients described experiencing an empathic relationship with their hospice nurses. The relationships consisted of two major categories- 'meaning of empathic nurse-patient relationships' and 'impact of empathic relationships on hospice patients'. 'Meaning of empathic

nurse-patient relationships' consisted of the sub-categories 'affirmation as a person' and 'friendship'. This relationship had an immense effect on the quality of life of these patients. The relationship with their nurse empowered the patients to cope and reconcile their needs and other issues experienced during this phase in their lives.

The paper does not give details of the four patients who did not describe empathic relationships with their nurses. Their interview data would have been interesting to ascertain how they perceived the nurse-patient relationship. However, the study highlights the importance of the nurse-patient relationship on the quality of life of the dying patient.

Field et al (1995) expanded on the notion of patients' experiences of their hospice care by exploring the responses of 28 terminally ill patients and their lay carers to identical questions about the patients' experiences in the month prior to their admission to an in-patient hospice. The study was a part of a larger study of client satisfaction with the Leicestershire Hospice (Field, Dand, Ahmedzai and Biswas 1992). Data were collected using structured interviews with patients and their relatives or other lay carers. The questions were identical to those used in the seminal work of Cartwright, Hockey and Anderson (1973).

The work of Cartwright et al was seminal because it was the first study about life before death. It was ground breaking in that it was methodologically rigorous, explored the needs of patients rather than professionals or policy holders, and 'dared' to explore a hitherto 'taboo' subject, such as death in detail. This research has been both acknowledged as a classic work and replicated in terms of methodology,(Cartwright and Seale 1990; Field, Dand, Ahmedzai and Biswas 1992; Addington-Hall and McCarthy 2001) over the last 30 years. The questions contained items on 'help with activities of daily living', 'the patient's symptoms', 'the patients' knowledge of their illness' and 'the care they received from doctors and nurses in the hospice and community'. The level of agreement between patients and family members was analysed using Wilcoxon's matched pairs signed-ranks test. Cohen's Kappa was also used to assess the agreement between patients and carers while controlling for chance agreement.

The results demonstrated that no statistically significant differences were found between the reports of patients or carers regarding the patients' activities of daily living, their physical symptoms, or the evaluations of the care they received. Discrepancies between accounts were most likely to concern the presence or absence of psychological symptoms, the degree of distress caused to patients by their symptoms, and the main symptoms experienced by the patient on admission to the hospice.

Much has been written on the use of carers as proxies in questions about palliative care (Cartwright and Seale 1990; Higginson, Priest and McCarthy 1994; Hinton 1999). Field et al are of the opinion that carers can act as reliable surrogates for patients in this area. This author believes that evidence presented by Fakhoury (1998) and her own experience tends to contradict this view. Moreover, if the patients had been interviewed on their own, their responses may have been different. They may have felt able to talk more freely about aspects of their care that they did not want to talk about in front of their relatives (see section 2.2.6)

Rasmussen and Sandman (1998) conducted a work sampling unit observational study in a hospice and oncology unit in Sweden. Data were collected using non-participant observation by two observers using a specifically designed observation form. In total, 5286 observations of patient activity were recorded. Patients were randomly selected to participate and then invited verbally and by letter. Data were analysed using descriptive statistics. The data were categorised into the six domains of the tool 'being with nurses', 'being with other health professionals', 'being with relatives and/or friends', 'being with fellow patients', 'being alone' and 'being out'.

The results indicated that there were significant differences between the two groups of patients related to time spent in each of the six domains during the day and night. Patients spent most of their time alone, particularly in the oncology unit. This meant not interacting with anyone else. Hospice patients also spent significantly more time with nurses, and their encounters were longer.

It may have been more helpful if the study had included more participant observation and field notes or interviews to discover what the patients felt about their care. They

may have been happy to be alone. Moreover, purely quantitative data cannot allow conclusions to be drawn regarding the quality of care provided.

The current state of knowledge regarding patients' perceptions of their hospice care indicates that they expect the hospice to provide them with physical relief from their illness. Patients tended to be satisfied with their hospice care and perceived that it provided a peaceful, calm and comfortable atmosphere. They also maintained that nurses and other staff spend more time with them in the hospice setting than other health care settings. The importance of a meaningful nurse-patient relationship with hospice nurses was also identified as important when dying.

Issues arising from the literature are that there is little consistency across studies in the views of patients regarding their hospice care. Most studies were small-scale descriptive studies, which did not allow patients to talk freely about their care. In addition, hospice care is notoriously rated highly by patients and their families anecdotally, when they are comparing it with conventional hospital care. Yet, no studies attempted to qualify or quantify this satisfaction.

In this researchers' experience, hospice care is often seen as the panacea of palliative care, particularly from a nursing viewpoint. It would seem pertinent, therefore, that in the current climate of cost effectiveness, efficiency and general public dissatisfaction in health care that a detailed exploration of patients' views of hospice care is worthwhile and timely.

2.2.3 The lived experience of terminal illness

No studies have explored the lived experience of being a terminally ill patient. Two studies have, however, explored the lived experience of life-threatening illness: chronic illness (Gullickson 1993) and cancer (Halldórsdóttir and Hamrin 1996).

In a phenomenological study exploring the perceptions of patients living with a chronic illness Gullickson (1993) collected data via unstructured interviews with a convenience sample of 12 individuals living with chronic illness. The interview transcripts were analysed using thematic content analysis by a team of nurse researchers.

The findings indicated that one constitutive pattern emerged; 'my death nearing its future' with the sub themes: 'awareness of not being', 'death: event or possibility' and 'a future of possibilities'. It was clear from the findings that each informant living with chronic illness brought close what 'we struggle to keep afar, our own death as a possibility'. Through the act of understanding the approaching of one's death, new possibilities for *being* emerged for the informants. This existential view of dying fits well with the phenomenological literature (Heidegger 1962; Gadamer 1994) and is particularly in keeping with Heidegger's views. Heidegger discussed the difference between *death as an event* and *death as a possibility of our own being* (Heidegger 1962). Heidegger suggested that for death to become meaningful for oneself it must be seen as a possibility. Those facing death have an opportunity to reflect on this possibility and consider their reactions to it.

The study provides an interesting perspective into how patients perceive chronic illness. However, Gullickson does not delineate her sample or explain the demographics of her sample, such as what diseases they suffered from, how old they were and for how long they had been suffering from chronic illness. Indeed, the sample may have included chronic illnesses such as diabetes, which although incurable do not mean that the individual is dying imminently. A different perspective may have been gained from cancer patients or terminally ill patients. Moreover, Gullickson does not state whether multiple interviews were constructed, to enrich the stories of informants and capture the lived experience of informants. Her study does however indicate the need for further research into this area.

On the other hand, Halldórsdóttir and Hamrin (1996) in a phenomenological study explored the views of a purposive sample of nine patients living with cancer in Iceland. Data were collected through multiple in-depth interviews (one-three interviews with each participant), with patients who were in the recovery or remission stage of cancer. The first interview involved the participants 'telling their stories' with no guide from the researcher. The subsequent interviews involved the researcher asking questions in direct response to the participants' descriptions, in order to arrive at a deeper level of understanding of their experiences. Although in keeping with phenomenology, this method makes any extension of the study by other

researchers and keeping an audit trail more difficult, (Koch 1994) as different questions were asked to each informant. Data were analysed using thematic content analysis using Colaizzi's framework.

The findings indicated that the overriding theme of the lived experience of having cancer was 'experiencing existential changes'. The sub-themes that emerged were 'uncertainty', 'vulnerability', 'isolation', 'discomfort' and 'redefinition'. Having cancer therefore appeared to involve uncertainties and a perceived lack of control, which can be anxiety provoking. The underlying unfulfilled need behind the uncomfortable feeling of uncertainty appeared to be the need for security and certainty and a sense of control.

All the participants in this study were in the remission or recovery stages of cancer and may have told different stories if they were dying. Moreover, the reality constructed within the research encounter is of that of the participants and as such is culturally and socially located. The researchers make the point that the experiences of Icelandic patients may differ from those in the rest of the world due to their specific cultural context.

These two studies provide an interesting perspective into the lived experience of patients with life threatening illnesses. However, neither study explicitly sought the perspective of dying patients, indeed the informants appeared to be 'physically able', and as such the findings are less relevant for this research. Moreover, the patients in Gullickson's study, who were living with chronic illness, were in touch with their own mortality and were able to discuss the meaning of their impending deaths. This emphasises the importance of conducting research with dying patients, by allowing them to tell their stories, and also that patients are willing to talk about their experiences.

The current state of knowledge regarding patients living with a life-threatening illness is that when death is certain patients' lives were dominated by uncertainty, vulnerability, and isolation, leading to feeling of lack of control. The overriding theme is of negativity. This does not however ring true to the researchers own

experiences of caring for dying patients, who often talked of their impending death as giving them a new lease of life by motivating them to live their life to the full.

Issues arising from the literature are the absence of any studies exploring the lived experience of dying patients. This may be due to the ethical issues already discussed in section 2.1, fear of attrition, or the difficulty accessing dying patients along their disease trajectory. However, despite the methodological and ethical challenges, if a high standard of palliative care, tailored to meet patient needs is to be achieved, research in this area is necessary.

2.2.4 Patients' views of pain and symptom control

As determined earlier (section 2.1) palliative care and the dying process are made up of psychological, social, physical, spiritual and existential components. It therefore seems pertinent to explore the literature related to patients' views of their physical and psychosocial needs.

Expanding on the notion of patients' perceptions of their palliative care needs, only one study elicited patients' views of their pain and symptom control (Higginson and McCarthy 1993). Higginson and McCarthy (1993) aimed to assess the validity of a measure of the outcome of palliative care (Support Team Assessment Schedule STAS) through comparisons of the views of patients and family members. The study used a survey research design to compare STAS ratings from two symptom control support teams in London. The sample size contained two support teams (both teams had nurses, doctors, a social worker and a secretary/administrator as team members), 84 patients and 67 family members. Data were collected by asking both teams to rate the 17 STAS items on all patients referred for care at referral, weekly, and then at discharge or death. Data were analysed using parametric statistics. Cohen's weighted Kappa was used to test for agreement between patients and family members and team ratings. Spearman correlations were also tested between team and patient ratings. This was then repeated for the team and family members. Mean (95% confidence interval) ratings were calculated for the items, which appeared normally distributed. A probability of $p<0.05$ was taken as significant.

Out of 183 patients referred to the support teams, 46% were interviewed indicating a high sample attrition. This appears to be a factor indicative of palliative care research (Cartwright, and Seale 1990, Twycross and Dunn 1994). The findings highlight that family members tended to rate physical problems as more significant than staff. The correlation coefficients were lower (0.20-0.66) than those found between staff and patient ratings. Moreover, the health care professionals rated pain control lower than patients and the family members rated it higher than patients. There were, therefore, significant differences in how staff, patients, and family members rated problems in palliative care.

It is widely acknowledged that pain and symptom control are essential components of palliative care (WHO 1990; NHCSPCS 1995), and are the most widely researched areas in palliative care, and subsequently have the most extensive evidence base (Twycross and Dunn 1994). However, only one study was identified that asked patients for their views about outcomes of palliative care. It follows that this area requires further investigation before a full picture can be elicited of patient views of their palliative care.

2.2.5 Patients' views of their psychosocial care

Psychosocial care in palliative care has been identified as being concerned with understanding and supporting patients within the context of their life experience, their family and others close to them, their social relationships and cultural environment (NCHSPCS 1997). Furthermore, psychosocial care includes issues of 'self-esteem, insight into, and adaptation to the illness and its consequences, communication, social functioning and relationships' (NCHSPCS 1997 p.3).

No studies have been identified from the literature search which explicitly explored patients' views of their psychosocial or spiritual care provided by nurses in palliative care. This is particularly interesting as palliative care as a discipline prides itself anecdotally as being able to provide good psychosocial care (NCHSPCS 1997). The fact that there is a poor evidence base here is a significant omission from palliative care research and requires claims from clinicians to be taken as anecdotal, rather than empirical evidence.

As indicated above, communication is perceived as a significant component of the psychosocial care delivered by palliative nurses, yet only one study was identified from the literature search, that elicited patients' views of nurses' communication skills (Bailey and Wilkinson 1998). The purpose of the study- part of a larger study (Wilkinson et al 1998) evaluating nurses who had completed a university validated course in cancer or palliative care in England- was to evaluate patients' perceptions of their nurses' communication skills and their concerns related to their illness. The second study aim was to determine the feasibility of comparing nurses' assessments with patients' perceptions of their current concerns. A sample of 36 self-selected patients with advanced cancer were invited to participate in the study. A total of 29 patients returned a self–report questionnaire consisting of seven open questions designed for the study.

The findings indicated that patients perceived a 'good communicator' to 'possess good verbal and non-verbal skills', including being a 'good listener' and being 'available to listen', 'demonstrate approachable personal attributes' and 'have knowledge of their subject'. The patients' major concerns were grouped into physical concerns, social concerns and psychological concerns. The majority of patients found discussing their concerns beneficial and felt it was a relief to talk. Only 19% answered the question 'what prevented you from discussing your concerns with the nurse'. Answers included 'the worry that I kept the nurse from her other duties' and 'I felt I was looking for attention'. Finally, the majority of patients (93%) indicated that they were satisfied with their interaction with the nurse.

Despite the fact that the study is the only study reported to have asked patients for their views of their nurse's interpersonal skills in palliative care, it was limited by the fact that a small survey design was used. More information and fewer unanswered questions could have been obtained by conducting face to face interviews. In addition, some information related to the methodology, in particular data analysis, is missing from the paper. However, the study does indicate the importance that patients place on good communication from the nurse. It also identifies the need for further research in this area.

The lack of studies related to patients' perspectives of the psychological role of the palliative nurse extends to studies related to the social support role of the palliative nurse. This is despite the fact that social support is indicated as an important component in coping with a terminal illness (Galbraith 1995; Krishnasamy 1996; Montazeri 1996; Grande, Todd, Barclay, Doyle 1996; Hinds and Moyer 1997; Lugton 1997). Indeed only one study was found that specifically asked patients for their views of their support needs in palliative care.

Grande et al (1996) used a descriptive research design to investigate how patients viewed the care and support provided by their professional carers. As an evaluation of their service delivery, one health authority (Cambridge) funded the study. The reported study is part of a larger study (Grande, Todd, Barclay, Betterton, Challis and Doyle 1994). The sample size comprised 43 patients, from a sample of 105 selected by the patients' general practitioners. Data were collected using semi-structured interviews conducted face to face.

The findings were obtained from 39 patients with cancer and four with non-malignant diseases. They indicated that 79% rated their general practitioner support as 'excellent' to 'very good', 88% perceived the support from their district nurses as 'excellent' to 'very good' and 94% perceived that the support that they were receiving from a Macmillan nurse was 'excellent' to 'very good'. The content of positive statements was grouped into four broad categories- 'psychosocial aspects', 'actions', 'clinical aspects', and 'general praise'. However, the way patients were asked about their care may have invited positive comments and could be considered a weakness of the study. In addition, general practitioners who were aware of the purpose of the study selected all the patients.

Current knowledge indicates that there is a weak evidence base regarding patients' perceptions of the psychological role of the nurse. Moreover, only one study identified patients' views of nurses' communication skills. This is despite claims anecdotally by palliative care professionals that specialist palliative care professionals provide communication and psychological care well. (see section 2.3.5). This weak evidence base may be because researchers and health care professionals view palliative care holistically, and therefore psychological care is

included within questions about palliative care as a whole. It may also be that patients do not raise psychological concerns to health professionals. This, however, seems unlikely when, key psychological concerns such as patient anxiety, and fear of death are known to be common among dying patients. Lack of research into the psychosocial role of the nurse, may however be because researchers and health professionals undervalue this aspect of the nurses' role.

2.2.6 Summary

The current state of knowledge regarding patient's perceptions of the role of the palliative nurse has revealed that patients want nurses to be responsive to their individual needs and to enable them to maintain their independence. Hospices were seen, as peaceful places where patients' physical needs would be met. The hospice nurse-patient relationship was perceived as important, particularly in relation to getting to know the patient. Furthermore, living with a chronic illness was characterised by a lack of control, and vulnerability.

The real issue is therefore that facing a terminal illness is, therefore, a stressful and fearful experience that impacts on all aspects of the life of the individuals involved. It has also been revealed that dying patients may have unmet needs in relation to their care. These are mainly in the areas of pain and symptom control, emotional support, and spending time alone.

A wide variety of research approaches have been used to qualify and quantify patients' perceptions of their palliative nursing care, mostly using small-scale descriptive studies. This reflects the lack of consensus regarding palliative care. Moreover, the majority of studies used very small sample sizes with no follow up of the patients in terms of a second interview or questionnaire. No studies specifically ascertained patients' views of the pain and symptom control aspect of the nurses' role and the psychosocial aspect of the palliative nurses' role. This is despite the fact that these components are an integral part of the palliative nurses' role.

Overall, these studies demonstrate the importance of ascertaining patients' views of their care. Nevertheless, none of the studies compared patient and nurse views and

none used a combination of research methods or a combination of care settings, indicating the need for further research in this area.

Another important issue to emerge from the literature is the question of whether dying patients should be interviewed on their own or in the presence of a relative or carer. The main tenet of the argument is that patients may not say the same things in an interview with a relative or carer present. They may fear upsetting their relative or may fear criticising their care if another person is present. Furthermore, their autonomy may be undermined by not giving them the right to be interviewed alone (see section 3.8.2, section 3.16.2).

It follows that in order to build a complete picture of the perceptions of palliative nursing that the views of palliative nurses need to be sought. The literature related to nurses' perceptions of palliative care will therefore be explored.

2.3 Nurses' perceptions of palliative care

Several authors (Quint 1967; Noyes and Clancy 1977; Williams 1982; Dunn 1992) have argued that the role of the nurse is fundamental to the care of the dying patient. There is, however, little consensus or agreement about what that function is or how best it should be described, and few researchers have explored this role in detail.

Previous studies (see Table 3) have explored the perceptions of the role of the palliative nurse from the perspective of nurses, patients and families. These studies are explored within the conceptual framework described earlier, but the researcher decided to exclude studies exploring families' perceptions for the following reasons. Firstly, this study aims to explore the views of patients and their nurses regarding palliative care and did not intend to explore families' perceptions of care. Secondly, this was a phenomenological, study, with a relatively small sample size and to include the views of families would have enlarged the study beyond the capabilities of the research method, and the time available for the study. Thirdly, evidence has shown that families' views of palliative care differ from those of patients, and they are therefore not the best proxy in terms of views of patient care (Higginson et al 1990; Hinton 1996; Fakhoury 1998). Finally, several previous studies have asked families for their views of palliative care (Higginson et al 1990; Cartwright and Seale

1990; Hull 1991; Sykes et al 1992; Davis et al 1996; Fakhoury et al 1997; Payne, Smith and Dean 1999). It could be argued that the reason that more studies have asked for families' views of patient care, than the patients themselves, is because carers are easier to approach and ask questions of than patients. It therefore follows that there is gap in the literature related to asking patients and their nurses for their views of palliative care.

Table 3 Studies exploring perceptions of palliative nursing care

	NURSES	**PATIENTS**	**COMBINATION OF TWO OR MORE OF NURSES, PATIENTS AND FAMILIES**
Author (s)	Samarel (1989)	Arblaster, Brooks, Hudson and Petty (1990)	Maher (1989)
	Davies and O'Berle (1990)	Raudonis (1993)	Masters and Shontz (1989)
	Degner, Gow and Thompson (1991)	Rasmussen and Sandman 1998	Higginson, Wade and McCarthy (1990)
	Steeves, Cohen and Wise (1994)		Ryan (1992)
	Rasmussen, Norberg and Sandman (1995)		Bergen (1992)
	Zerwekh (1995)		Hunt (1992)
	McClement and Degner (1995)		
	Byrne and McMurray (1997)		Higginson, and McCarthy (1993)
	Taylor, Glass, McFarlane and Stirling (1997)		Cox, Bergen and Norman (1993)
	Larkin (1998)		

The literature on nurses' perceptions of their role in palliative care tends to be of poor quality and fraught with methodological problems. The studies are largely small-scale, descriptive and exploratory (see section 2.3). In addition, the majority of studies used a convenience sampling technique, the weakest of non-probability sampling techniques (Polit and Hungler 1999). Moreover, few studies make any

comparisons across different care settings, indeed, most studies were conducted in only one care setting. Furthermore, few studies give an interpretation of the caring aspect of the nurse's role.

Some authors (see section 2.3.2) have, however, attempted to explain how nurses perceive their role in palliative care and what they perceive are the key elements of palliative nursing care. In the following sections, the reviewed studies are divided into, the 'expert'/ 'good' nurse in palliative care, supportive role of the nurse, the experience of being a hospice nurse, behaviours and characteristics of the palliative care nurse, the nurses' role in providing psychological and spiritual care and the nurses' role in providing pain and symptom control. These issues are important within the context of care provided by nurses to dying people and establishing nurse-patient relationships in palliative are. They, therefore, form an integral part of the focus of this study.

2.3.1 'Expert'/ 'good' nurse in palliative care

The common understanding of an expert is someone whose special knowledge or skill causes him/her to be an authority in a particular field or area. Likewise, expertise consists of expert knowledge or opinion. Since the seminal work of Benner (1984), researchers have become interested in defining the nature of expert nursing practice).

Benner (1984) was seminal because it was the first study to define the nature of expertise in nursing practice. It was also one of the first studies to articulate *how* nurses practise and to explore and define nursing knowledge. Benner was also one of the first nursing researchers to use a phenomenological methodology in her research, she, therefore, set the scene for a new phenomenological method unique to nursing. In addition, her work inspired other researchers to explore the nature of nursing expertise (Gordon 1986; Steele and Fenton 1988; English 1993; Darbyshire 1994; Cash 1995; Lauri and Salantera 1995; Macleod 1996; Paley 1996; Benner, Tanner and Chesla 1996; Rolfe 1997; Wolf 1999. Benner's work has been both widely acclaimed and criticised, producing a healthy, critical debate (English 1993; Darbyshire 1994; Cash 1995; Paley 1996). Her work has also been extended (Reed 1994; Lauri and Salantera 1995; Maynard 1996; Macleod 1996; McElroy 1996) and

operationalised in practice (Gordon 1986; Carlson, Crawford and Contrades 1989), and used as the basis for nursing curriculae (Nicol, Fox-Hiley, Bavin and Sheng 1996).

Clinical expertise, however, tends to receive scant attention in the research literature and is under valued (Macleod 1996). An exploration of the knowledge and skills of experienced practitioners, allows 'hidden' or 'everyday' caring practices to be revealed (McFarlane 1976; Benner 1984). Everyday caring practices are often difficult to articulate because of their complexity and reliance upon context for meaning. An in-depth exploration of expert nursing practice can allow the relationship of expertise to clinical competence, to be uncovered. Although it is still unclear just how expertise develops, the close link between experience and becoming an expert involves deployment, and development of knowledge and skills. Moreover, expertise in nursing is recognised to include a combination of theoretical knowledge (knowing-that) and practical knowledge (knowing-how) (Benner 1984; Macleod 1996).

As Benner's study was a seminal work and because her study set the scene for future work on expertise in nursing practice, it seems pertinent that this study is reviewed in depth. Benner (1984) used Heideggerian phenomenology in both her study of clinical expertise in nursing and in her later study into caring and its relationship to stress in nursing (Benner and Wrubel 1989). The 'Novice to Expert' study was a United States government-funded project to develop methods of evaluation in seven participating schools of nursing and five hospitals in San Francisco. The aim of the study was to examine the differences between practical and theoretical knowledge in nursing by providing examples of competencies identified from the study of nursing practice, describing practical knowledge, and outlining strategies for preserving and extending that knowledge.

Benner used Dreyfus and Dreyfus's (1986) model of skill acquisition (novice, advanced beginner, competent, proficient, expert), which had been developed through a study of chess players and airline pilots, as a framework for her study. The study was undertaken in order to further delineate and describe characteristics of

nurse performance at different stages of skill acquisition, and to attempt to apply the skill acquisition model to nursing. The goal of Benner's work, therefore, was to find 'exemplars' that embodied everyday practices and experiences. A sample of 21 pairs of nurses was obtained from three hospitals in San Francisco where preceptors (expert nurses) were used to orientate newly qualified staff nurses (novices). The sampling technique was not stated. Each member of the pair was interviewed separately about patient care situations they had encountered and which stood out for them, using a form of critical incident technique. In addition, interviews and participant observations were conducted with additional experienced nurse clinicians (n=51), newly graduated nurses (n=11) and senior nursing students (n=5).

The interviews were tape recorded and transcribed verbatim. Three related interpretative processes in the data analysis were used- thematic analysis, analysis of exemplars and search for paradigm cases. The intent was not to come up with theoretical terms, but to identify meanings and content.

The findings described the performance characteristics at each stage of the Dreyfus model as well as identifying the teaching learning needs at each level. For instance, Benner stated that the expert nurse has an intuitive grasp of clinical situations without a need for rules or guidelines to understand a particular situation. She asserted that expert clinicians are not difficult to recognise because they frequently make clinical judgements or make complex situations in a remarkable way. Likewise, experts teach others by describing clinical situations where their intervention made a difference, thereby enabling their knowledge to become visible. She also postulated that not all nurses could become experts.

Benner was ground breaking in that she moved the emphasis towards the clinical practitioner and clinical practice and away from formalisms such as nursing models. Moreover, Benner provided a sophisticated critique of the rationalist tradition in nursing. Her position relies on the difference between practical and theoretical knowledge, using the perspectives of Heidegger (1962), Kuhn (1996), and Polyani (1998). A strong theme in the Benner argument is related to intuition and its place in clinical thinking.

A significant limitation of the study is the fact that Benner holds that expertise is contextual; in other words, the expertise is determined by the situation in which the expert is working (English 1993; Cash 1995). This notion impedes the identification of expertise, as expertise is determined by the clinical ward environment and not by the individual themselves. Moreover, Benner's study was context laden, as the United States nursing curriculum had less clinical practice than the United Kingdom at that time. Benner's use of intuition has also been criticised (English 1993; Cash 1995). English argued that Benner does not clarify the concept of intuition, and how the nurse can become intuitive. Conversely, Darbyshire (1994) asserted that Benner did, in fact, make the concept of intuition clearer. Skilled, everyday knowing is markedly different from formalised or empirical knowledge and that intuition only occurs, according to Benner (1984), in 'situations where a deep background understanding of the situation exists'. Cash (1995), however, indicated that Benner does not explain that, in nursing, there is a relationship between intuition and the exercise of power. Cash asserted that, without power, intuition cannot be utilised in judgement situations.

This researcher believes that in nursing generally, and in palliative care particularly, intuition is a key skill of an expert nurse. Intuition will be part of an expert nurses' developing clinical knowledge, which she will use in a range of clinical situations, such as assessing pain and symptom distress.

Further weaknesses in Benner's study are related to the fact that she mixed methodologies in data analysis without clearly stating that this is what she was doing. In terms of the philosophical underpinnings to the study, the term 'interpretative strategy' was used, based on Heideggerian phenomenology. However, Benner additionally used the constant comparative method to analyse the data described by Glaser and Strauss (1967), based on their grounded theory. These two methodologies are, however, diverse in their philosophical origins. Nevertheless, the contribution of Benner to the development of nursing knowledge is useful, particularly in relation to the recognition of practical knowledge and clinical expertise.

Despite the fact that palliative care is an acknowledged specialism there is little research describing expert nurses in palliative care. Only three key studies were identified (Degner et al 1991; McClement and Degner 1995; Zerwekh 1995). These are analysed below. Furthermore, this lack of literature does not correlate with the rapid expansion of clinical nurse specialists in this area. There are now over 2000 Macmillan clinical nurse specialists in the U.K (Macmillan Cancer Relief 2001) and a large number of graduate and post-graduate courses for palliative nurses. Moreover, palliative nursing as a whole, and care of the dying, in particular, involves a great deal of practical knowledge. Indeed, it has been argued that in the last 48 hours of life a patient predominately requires nursing care (Noyes and Clancy 1977; Williams 1982; Dunn 1992). It therefore follows that this is an area that requires investigation.

For instance, a Canadian qualitative study undertaken by Degner et al (1991) developed and tested a model of expert nursing practice in the care of the dying patient. A purposive sample of 10 nurse educators and 10 experienced palliative care registered nurses - drawn from one palliative care unit -were selected for the study.

Data were collected using a semi-structured interview guide to elicit a description of the behaviours the sample associated with positive and negative attitudes to care of the dying. Each informant was asked to describe situations in which student nurses or their colleagues had displayed very positive or very negative attitudes towards care of the dying. Data were content analysed using an independent coding technique. The findings were then subjected to content validation by comparing them with a review of the literature on 'comfort care', 'pain control', 'communication with the dying', 'supporting colleagues', 'respecting the patients' rights' and 'family care'. The findings were not altered in this procedure, but compared as a way of testing for rigour

The critical behaviours identified in the study were- 'responding during the death scene', 'providing comfort', 'responding to anger', 'enhancing personal growth', 'responding to colleagues', 'enhancing the quality of life during dying' and 'responding to the family'. The findings emphasised the importance of responding to patients' feelings, an area sometimes overlooked in the care of the dying patient

(Wilkinson 1991; Heaven and Maguire 1996; Booth, Maguire, Butterworth and Hillier 1996).

The study is limited by its lack of information on the research design and methods used. However, the researchers indicate that this is a precursor to a larger study to define a model of expert nursing practice using comparative samples of nurses from a variety of clinical settings. The critical behaviours could, thus, serve as a beginning guide for structuring nurse education programmes about care for the dying.

Further work on the model is described in a later paper (McClement and Degner 1995). In a descriptive, exploratory, study the researchers built on previous work (Degner et al 1991) by using 10 intensive care nurses as respondents. The interviews were analysed to identify essential nursing behaviours. These were categorised by the first author, not involved in the original study, using the coded interview data, and then checked against the original data by Lesley Degner. Six of the general categories of behaviours were found to be analogous to the categories generated in the original study. Several important differences were noted. For instance, the category 'enhancing the quality of life while dying' did not emerge as a distinct theme in the later study. Moreover, family care was less apparent with the ICU nurses, particularly at the time of dying. ICU nurses also emphasised the importance of keeping family informed during the transition from curative to palliative care. The later study, although highlighting some differences further accentuated the use of the expert nursing behaviour descriptors as a framework for studying education programmes about care of the dying.

In a qualitative grounded theory study Zerwekh (1995), explored the experience of hospice nursing from the perspective of a convenience sample of 32 expert hospice nurses in Washington State U.S.A. Expert hospice nurses were defined as 'having at least five years experience and being those to whom others turned to for hospice clinical advice'. The experts were all chosen by the hospice home care supervisors. Data were collected using in-depth interviews within a story-telling framework. The nurses were asked to 'tell stories' of memorable practice experiences.

The findings indicated 10 competencies that were conceptualised within a figurative model in the image of a tree. The competencies were 'collaborating', 'comforting', 'guiding letting go', 'connecting', 'encouraging choice', 'caring spiritually', 'strengthening the family', 'reaching out to meet fear' and 'sustaining oneself'. The core category was 'speaking the truth' determining all branches of the competencies.

The categories provide a model that can usefully be used as a framework to guide practice for hospice nurses. However, there are flaws to Zerwekh's study. The definition of 'expert nurse' in hospice care was linked primarily to experience (see section 2.11.7 and the critique of Benner's work). Zerwekh indicated that she was 'inspired by' Benner (1984) but does not critique Benner's work including her definition of an 'expert nurse'.

Current knowledge therefore indicates that an expert /good palliative nurse provides comfort, enhances quality of life during dying, responds to patients' feelings, provides spiritual and emotional care and is involved with family orientated care. The real issues are, however, that few studies were identified which explored the concept of an expert /good palliative nurse, none of which were undertaken in the U.K. This researcher had not anticipated this, given the emphasis of clinical nurse specialists (CNS) in British palliative care practice and their use as role models for other CNS's practice. Furthermore, the lack of evidence is unexpected, due to the influence of Benner's work on nursing curricula and inclusion in many graduate and post- graduate nursing courses.

2.3.2 Supportive role of the nurse

Several studies have explored the supportive role of the nurse in palliative care (Davies and O'Berle 1990; Steeves, Cohen and Wise 1994; Larkin 1998). An area that could be argued to be a component of a good/ expert palliative nurse. These studies vary in their approach and rigour, but all describe how the nurse perceives his/her role in palliative nursing care. Indeed, it is interesting that the assumption is made that the nurses' role is supportive, despite the fact that there is little evidence to substantiate the psychosocial role of the palliative nurse (see section 2.2.5 and 2.3.5). Nevertheless, these studies are widely used as evidence into the importance of the nurse providing comfort and support to the dying patient.

An exploration of the role of the nurse in palliative care is provided in a study undertaken in Vancouver, Canada, (Davies and O'Berle (1990; 1992). This study has anecdotally had an impact on many palliative nurses, who perceive that the study either provides a detailed account of their practice, or provides an account of how they would like to practice. There is however, no empirical evidence to substantiate these perceptions.

The purpose of Davies and O'Berle's grounded theory study was to describe the clinical component of the nurses' role in palliative care. Data were collected using in-depth descriptions of the care given by one clinical nurse specialist to 10 patients and their families. This totalled 25 hours of interviews. Constant comparative analysis revealed that the nurses' role was a supportive one with multiple dimensions. The researchers developed a model of the palliative care nurse from the findings which consists of six interwoven, but discrete, dimensions- 'valuing', 'preserving integrity', 'connecting', 'empowering', 'finding meaning' and 'doing for'. Some of these dimensions were regarded as attitudinal (preserving integrity), while others were task-orientated or action dimensions (doing for, connecting, empowering, finding meaning). All dimensions are regarded as playing a vital part in the support process (Davies and O'Berle 1990). Davies and O'Berle considered 'valuing' as a contextual dimension in that it provides the context within which supportive care can occur. In order to be supportive, the nurse needs to believe in the inherent worth of their patients and in their strengths and capabilities. 'Connecting', in essence, referred to forming a bond with the patient. 'Empowering' implied that the nurse helped patients to find or build strength within them. 'Finding meaning' involved helping patients make sense out of what was happening in the world of the health care system. 'Doing for' is the aspect of nursing care that involved the provision of physical care and is not supportive unless interwoven with the patient. In other words, 'doing for' behaviours can become empowering, can help the patient to find meaning and can help to maintain the connection between the nurse and the patient. Moreover, although the four do not necessarily occur in any particular order, some degree of 'connecting' must occur before other dimensions can appear. 'Preserving integrity' is the core concept. The authors argued that nurses must maintain their own wholeness if they are to provide support to others. A notion that was reiterated

by the work of McWilliam, Burdock and Wamsley (1993) who argued that preservation of integrity was a vital factor in maintaining role adaptation and intrapersonal and interprofessional conflict management for the palliative care clinical nurse specialist nurse in Canada.

Davies and O'Berle's study provides an in-depth, novel conceptual model of palliative nursing care that has since been validated in practice (Davies and O'Berle 1992). In their second paper on their study (Davies and O'Berle 1992), the authors evaluated and tested their supportive care model. They did this by giving presentations on the model to 'numerous groups of nurses in a variety of settings' who were asked to provide feedback to the authors. The feedback indicated that the model had captured the dimensions of their own nursing roles. The authors do not give any information on the range of nurses spoken to, or details on the clinical settings. However, the authors use this an example of the validity and rigour of the content of the model (Miles and Huberman 1994).

Arguably, the major flaw and limitation of the study is that only one informant was used and who relied on her reflections of her own practice over a period of time, rather than recounting more immediate experiences. While palliative care research is starting to use research designs that rely on one informant (Twycross and Dunn 1994), the study could have been expanded into a larger study using an increased sample size drawn from a range of practice settings. The weaknesses of this study, therefore, limit its usability and although the model produced, and the concepts identified, are interesting, the methodological flaws and subsequent bias indicate the need for conducting new research in this area, with a different research design.

In addition, Steeves, Cohen and Wise (1994), as part of a larger study (Cohen, Haberman and Steeves 1994), conducted a phenomenological investigation in order to ascertain oncology nurses' perceptions of the meaning of their work, including working with dying patients.

The findings indicated that the nurses perceived that they fulfilled three roles- 'maintaining the goals and values of health care', 'nurses' participation in the personal lives and experiences of patients and their families' and 'reconciling the

goals of healthcare professionals and the experiences of patients'. The findings also portrayed a feature that the researchers referred to as the 'isolating feature' of oncology nursing. This referred to the fact the nurses in the study did not talk to other nurses or anyone else about their relationships with patients, a feature not alluded to in previous literature.

More interesting findings could have been elicited by speaking to the patients themselves, a factor noted by the researchers. Moreover, the cultural context of the United States health care system means that the replication of the study in the U.K. may have revealed different findings.

A study conducted along a similar theme was undertaken by Larkin (1998). This research undertaken in the Irish Republic used hermeneutic phenomenology within Gadamer's (1994) framework to explore the lived experience of Irish palliative care nurses. A purposive sampling technique was used to recruit 16 registered palliative care nurses working in a palliative home care setting.

The findings elucidated five themes; 'dluchaidreamh' (closeness), 'anam chara' (soul-friend), 'gramhar' (loving), 'aire' (caring) and 'spioraid' (spirit). 'Closeness' referred to the fact that nurses were drawn closely together with the patient and their family at the time of death. 'Soul-friend' referred to the role of the palliative care nurse as adviser, supporter and care–provider and was allied with Celtic monastic tradition describing a form of spiritual direction. For the informants in the study, it reflected the honesty and openness necessary to care for a dying patient which, for them, held a sacred quality and reflected the connectedness in relationships with- rather than doing for- and is reflected in the work of Golberg (1998). 'Loving' was used by the respondents to denote a quality of warmth and loving in the nurses' interactions with their patients. It encapsulated the ideal of sharing, reciprocity and rapport that the respondents shared as Irish palliative care nurses. This concept is also reflected in the work of Campbell (1984) and Jacono (1993). All respondents viewed 'caring' as an important concept. Caring was seen as central to their role and the nurses described their ability to care in terms of selflessness, deepness and effusiveness. The nurses also put much emphasis on having time to care. 'Spirit'

referred to the importance of spirituality in the nurses' personal world and their professional world.

Although there were parallels between the findings and previous literature, there is a repeated sense that the Irish perspective of living and dying differs from current European perceptions of the phenomena (Walter 1994), few generalisations can, therefore, be made in terms of describing the role of palliative care nurses. Moreover, the interviews were conducted on only one occasion with most respondents. The existential phenomenological literature suggests that multiple sources of data enrich the quality of the study (Benner 1994; Koch 1996; Crotty 1996).

Current knowledge therefore reveals that the supportive role of the nurse is facilitative and grounded in caring. The emphasis is on the interactive relationship between nurse and patient, characterised by emotional support. The studies are distinguished by emotive language in their findings, striking at the heart of the empathic nurse-patient relationship. This researcher would argue that this is one of the main reasons why palliative care nurses often identify with these studies and they are frequently used and quoted in papers and articles and academic essays by palliative nurses. However, this adherence and devotion to these studies does not take in to account the serious methodological flaws, (namely, small-scale, bias and context specific) which this researcher believes detract from their importance and usability. More research in this area is therefore urgently needed.

2.3.3 The experience of being a hospice nurse

It has been suggested that the role of the nurse in palliative care is directly related to the setting in which nurses practise (Thompson 1986; Reisetter and Thomas 1986; Brockopp, King and Hamilton 1991; Irvine 1993). When hospice nurses are compared with other groups of nurses, particularly nurses from the acute setting, it has been shown that they experience less death anxiety (Bene and Foxall 1991; Payne, Dean, Kalus 1998) and more positive attitudes towards death (Kirscling and Pierce 1982; Field 1989; Brockopp et al 1991). In addition, it has been argued that hospice nurses experience less occupational stress than nurses in other care settings (Vachon 1995; Dean 1998), although the need for support in this area of nursing is

acknowledged (McKee 1995). It therefore seems pertinent to explore the literature, particularly pertaining to this group of nurses in palliative care.

However, few studies have explored the role of the hospice nurse in depth (Samarel 1989; Rasmussen et al 1995; Byrne and McMurray 1997). For instance, in a descriptive study conducted in a hospice in New Jersey, U.S.A. Samarel (1989) explored the ways in which a group of hospice nurses met the needs of both terminally and acutely ill patients. Data were collected via participant observation of nursing practice during a 12-month period in a combined hospice and acute care unit. The researcher kept detailed field notes. All ten nurses employed by the hospice participated in the study. Data were analysed using the constant comparative method described by Glaser and Strauss (1967).

The findings indicated that nurses interacted with both dying patients and acutely ill patients using touch, language, and psychological and spiritual care. The nurses were able to adjust from their therapeutic role (acutely ill) to their supportive role (dying patients) fairly easily, an issue Dunn (1992) identified to be a particularly difficult issue. The study is limited, as the methodological description is weak. The authors describe, in effect, an ethnographic study, but make no mention of this. Moreover, they used a grounded theory method to analyse their data when it is not described as a grounded theory study. The description of the findings is weak, considering the amount of data which must have been generated during a 12-month period of participant observation. In addition, generalisations are impossible, as the study was conducted in a hospice setting that- unusually- also had acute beds.

Likewise, a Swedish study conducted by Rasmussen et al 1995) outlined the experience of becoming a hospice nurse using a phenomenological approach. A convenience sample of 19 registered hospice nurses (14 RNs and five LPNs) was chosen. All the nurses were employed in Sweden's first purpose-built hospice. In-depth interviews were employed, based on a narrative framework inspired by the work of Ricoeur (1976) which employed broad open-ended questions to guide the narrative process. The data were analysed using a phenomenological hermeneutic approach. The two theme categories were 'meaningful nursing care', which contained stories of nurses experienced in terminal care and 'nurses as people',

which contained stories of nurses inexperienced in terminal care. The sub-themes elicited were 'the opportunity to work in a setting that acknowledges death', 'the opportunity to form close relationships' and 'the opportunity to use personal and professional qualities'.

The need for further research is indicated by this study, particularly in relation to gaining the views of patients and relatives as well as nurses regarding the nature of hospice nursing. In addition, the researchers do not state whether single or multiple interviews were conducted with participants, a necessary criteria when conducting phenomenological studies, particularly with healthy participants (Benner 1994; Crotty 1996; Koch 1996).

Byrne and McMurray (1997) conducted a phenomenological study in a hospice in Western Australia. Data were obtained from a purposive sample of nine experienced hospice nurses employed in the hospice via in–depth interviews which were employed using an open-ended format. Data were analysed using Colaizzi's (1978) method of analysing phenomenological interviews in combination with recorded observations of non-verbal data and the researcher's reflective notes. Triangulating data analysis in this way provides greater depth of information than would have been possible using a single source (Miles and Huberman 1994). Formulated meanings were clustered into 18 provisional themes, which were returned to participants for verification; additional comments from the nurses were then added to the data. The themes emerging from the data demonstrated that nurses were 'transformed by their experience of caring for dying patients' and that the 'hospice context influenced caring'. 'Caring was embodied in nurse-patient interactions' and caring was extended to patients' families. Finally, nurses developed 'coping' strategies to help them come to terms with their experiences. These involved 'caring for selves' 'keeping work in perspective' 'managing stress' and 'emotional distancing'.

The implications of the findings are that awareness of the effects of their caring activities on patients, their families and themselves is essential in order to allow hospice nurses to look after themselves and thus to facilitate their enabling of patients to make choices regarding their care. This ability to recognise when patients need to discuss issues has been found in other studies on the role of the palliative

care nurse (Davies and O'Berle 1990; Degner et al 1991). The study also highlights the need for further research into the influence of context on nurses' ability to care.

Current knowledge therefore demonstrates that hospice nursing is characterised by the interaction between nurses and patients, family care, psychological and spiritual care, close relationships between patients and nurses and the significance of the nurse developing coping strategies to help them cope with their stressful experiences. Moreover, caring predominated nurse-patient interactions. In addition, the hospice environment influenced caring.

However, despite the fact that the modern hospice movement has been around for over 30 years and the importance placed on nursing in the speciality of palliative caring, it is surprising that so few studies have explored the experience of being a hospice nurse. In addition, although the hospice movement was founded in the U.K., none of these studies was conducted in the U.K.

2.3.4 Impact of death and dying on the palliative care nurse

It has been argued that the care of dying patients and their families is different from ritualised general nursing practice, because it involves physical as well as emotional labour (James 1986; Field 1989; Wakefield 1999). Indeed, Wakefield found that when nurses in a surgical ward were caring for dying patients, that they were more likely to spend more time with the patient and adopt holistic care. Nurses were also observed to engage in sensitive, and more sedate forms of practice, such as the use of touch, patience, empathy, and tenderness. It may be that it is these caring aspects of palliative nursing that nurses who choose to work in palliative care find attractive. It has been suggested that a need for emotional reward plays a part in the motivation to work in a hospice (Vachon 1995). Other reasons are a sense of calling or vocation and previous personal experience (Vachon 1995). Moreover, Rasmussen et al (1995) identified that hospice nurses were motivated by the desire to have an opportunity to form close relationships with patients and families.

It has been further identified that care of the dying by nurses can be a stressful and demanding experience (McKee 1995; Booth 1995; Vachon 1995). There is evidence that nurses often experience feelings of inadequacy and inability to cope with pain

management and symptom control (Copp and Dunn 1993). Other studies have identified that palliative nurses have a more positive attitude towards death, experience less death anxiety, have a greater sense of personal control, and have less fear concerning their own mortality and the death of other, than nurses working in non-palliative care areas (Kirscling and Pierce 1982; Thompson 1986; Field 1989; Brockopp, et al 1991; Payne et al 1998). Studies have also indicated the importance that education about palliative care has on influencing nurses' attitudes to the dying (Yeaworth, Kapp and Winget 1974; Caty and Tamlyn 1984; Degner and Gow 1988a; Degner and Gow 1988b; Hurtig and Stewin 1990; Corner 1990).

A small number of studies have identified the behaviours and characteristics of palliative nurses. For instance, in an exploration of the issue of palliative nurses' behaviour and characteristics, Ryan (1992) revealed that nurses' behaviours related to psychosocial needs were significantly more helpful than behaviours related to physical needs ($p=<0.05$). Likewise, Taylor et al (1997) indicated that nurses perceived that palliative nursing meant 'dealing with death', 'making connections', 'making contracts', 'acting as an advocate' 'building interpersonal relationships', 'requiring family and colleague support' and 'being involved in issues'.

Few exploratory studies have, therefore, examined the involvement, motivation and characteristics of nurses caring for dying patients. These have mostly focused on nurses working in hospices. Furthermore, because of the multiple needs of the dying person, the focus and scope of these studies vary. It is clear however that nurses use a range of strategies and mechanisms to negotiate, develop, and maintain relationships with dying patients. The effects of short and long-term involvement of nurses with dying patients are still poorly understood, although there is an indication that it is a stressful experience. Moreover, there is little evidence of the motivation of nurses to work in palliative care. The experience of this researcher suggests that nurses who choose to work in specialist palliative care are often dedicated, caring people with a sense of humanity, who often possess spiritual or religious beliefs. These nurses often, therefore avoid the 'cut and thrust' of acute areas and 'high tech' areas and prefer instead the slower, more individualised pace of a hospice setting. This researcher would also suggest that there is also speculation, but no evidence base, to suggest nurses choose palliative care because of previous experience

regarding loss or death and the subsequent 'need to be needed'. However, until further research is undertaken, the long-term impact on nurses who are exposed to death and dying and the reasons why nurses choose to work in palliative care remains unclear.

2.3.5 The nurse's role in psychosocial and spiritual care

Given that the WHO definition of palliative care (WHO 1990 section 2.0.3), as well as the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS 1997) identify the importance of the psychosocial and spiritual component of palliative care it seems that it is worth exploring the literature in this area.

However, despite the importance attributed to the psychosocial and spiritual care of the dying, there are few studies exploring this component of the palliative nurse's role. Much of the literature related to the palliative nurse's role in psychosocial care is primarily concerned with their role in providing effective communication (Wilkinson 1991; Heaven and Maguire 1996; Booth, et al 1996). These studies are therefore discussed in this section.

Communication by nurses and other health professionals with dying patients is often identified as poor (Wilkinson 1991; Booth, et al 1996; Heaven and Maguire 1996; Chan and Woodruff 1997). Recent research has attempted to work towards rectifying this problem by reviewing communication skills programmes to address this deficit in skills (Faulkner 1992; Andrew 1996; Wilkinson, Roberts, Aldridge 1998; Wilkinson, Bailey, Aldridge, Roberts 1999; Booth, Maguire, Hillier 1999). The current emphasis is on skills programmes that are embedded within an existing university-validated specialist course in cancer or palliative care (Wilkinson, et al 1999).

For instance, in a analytical relational survey conducted in two hospitals in England, Wilkinson (1991) explored nurses' views, feelings and difficulties about communicating with cancer patients and the extent to which nurses facilitate or block patients and their awareness of any blocking behaviours. The study also explored the relationship between nurses' verbal behaviours and levels of anxiety, social support,

work support and attitude to death. Data were collected from 54 registered nurses using several methods- a questionnaire containing demographic data, fear of death scale, a social support questionnaire, and an anxiety inventory. A tape-recorded nursing history with a newly diagnosed cancer patient, a patient admitted with recurrence, and a patient admitted for palliative care were also undertaken. A semi-structured, tape-recorded interview on the difficulties of caring for patients was employed as well. Field notes were also kept regarding contextual data. The quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS), and two independent psychologists rated the tape-recorded histories. The semi-structured interviews were analysed using content analysis.

The findings indicated an overall poor level of facilitative communication, with a patient's recurrence of cancer causing most difficulties for the nurses. On the whole, the nurses were poor in the area of psychological assessment, with few nurses asking patients if they had any worries. The analysis of verbal behaviours revealed four different styles of communication employed by nurses- 'facilitators', 'ignorers', 'informers' and 'mixers'. Analysis of variance also demonstrated that there were significant differences in blocking behaviours between wards, indicating that the context of care or ward environment was a significant factor in determining how nurses communicate with patients. Multiple regression analysis also indicated significant variables in the prediction of facilitative verbal behaviour. These were ward environment, cause of stress (nurses who stated that their stresses resulted from giving poor care were the best facilitators), support from managers, education in cancer care, nurses' own feelings about communicating with patients, and nurses interests outside nursing. Similar significant variables were found to contribute to the nurses' blocking behaviours, ward, religious beliefs, self-awareness, fear of own death, level of anxiety and time committed to outside interests.

More recent research has explored the ability to communicate not just with cancer patients but with dying patients (Booth 1993; Heaven and Maguire 1996). For instance, for a PhD study, (Booth 1993) conducted a prospective study in two hospices in the North of England to assess the impact of training 41 hospice nurses in assessment skills. The training element of the study consisted of six training sessions. Using a mixed method approach, every nurse was tested using a short

questionnaire to gain demographic data. A second questionnaire used four-point scales to indicate the nurses' perceptions of the importance of interviewing skills, followed by a semi-structured interview to elicit what support the nurses had received in relation to specific incidents and their response to this. In addition, each nurse completed a validated social support questionnaire. The nurses were then asked to interview a hospice patient not known to them lasting approximately 20 minutes. This interview was audio-taped and rated for the time the patient spent expressing or mentioning feelings.

The results indicated a large sample attrition, mainly from nurses who left the hospices during the course of data collection (18 months). The results identified that blocking behaviours were most evident when patients disclosed their feelings (Kendalls $r=0.36$, $p<0.001$). In interviews containing most patient disclosure of feeling, blocking was significantly less ($r=-0.24$, $p<0.5$). In those interviews containing the most disclosure by patients the nurses indicated that their direct supervisor was concerned about the welfare of the nurse and therefore supported them through difficult communications. Moreover, it was likely to have been a supportive environment as all nurses employed by the hospice took part in the education programme which was tested in the study.

The findings contradict those of Seale (1991a) who found that communication is better than average in hospices. For the majority of patients in Booth's study disclosure of feelings was met by overt avoidance and failure to clarify their concerns by nurses. The findings also indicate the need for support from supervisors in improving the nurse's skills and the need for peer staff support. The findings are also inconsistent with the work of Hunt and Meerabeau (1993) who suggested that terminally ill patients do not want to disclose their feelings to nurses. However, in Booth et al's study it was the nurses who led the patient away from feelings or concerns, indicating that the patients did want to discuss their concerns with nurses.

A similar study was conducted in the North of England (Heaven and Maguire 1996; 1997) who were based, like Booth, in the Cancer Research Campaign Psychological Medicine Group in Manchester. The study aimed to determine the effect of assessment skills training on both the structure and process of nurses'

communication skills as well as the clinical outcome of communication. A sample size of 22 nurses completed all three assessments.

The results demonstrated that skills improved from pre-post assessments and post-follow up assessments. Wilcoxon signed-ranked tests were used to test the significance of these results. An increase in open questions used from pre-post assessment and post-follow up assessments was found to be significant ($p<0.001$). An increase in psychological focus was found to be approaching significance ($p=0.005$). Blocking was not found to be as evident as in Wilkinson's (1991) study. Video demonstration and use of audio feedback was, therefore, found to improve skills as in previous studies (Faulkner and Maguire 1994). This did not, however, achieve statistical significance until follow up, suggesting that using these skills in clinical practice with colleagues who had attended the same communication skills course was a significant factor in the improvement of psychological care. However, the study significantly demonstrated the lack of improvement in the outcome of communication. For instance, the nurses displayed an inability to elicit and identify their patients' concerns, despite the extended use of skills known to increase patient disclosure.

Despite the volume of literature indicating that nurses often communicate poorly with patients, much of the research appears to make assumptions about nurse-patient interactions, particularly about what is happening, and why. Nurses are sometimes given the chance to explain their actions and give their views, but patients are rarely given this opportunity. Implicit in the analysis of nurses' communication skills is the idea that patients want to tell nurses their concerns, and will do so provided the nurse encourages, and does not block them. The evidence around the influence of care setting on nurses ability to communicate is however contradictory. The assumption that palliative nurses are better communicators than other nurses therefore has a weak evidence base.

There is an increasing literature on the nurse's role in providing spiritual care for dying patients (see Dyson, Cobb and Forman (1997) for a systematic literature review). The literature tends to indicate that this role is often misunderstood (Narayanasamy 1993; McSherry and Draper 1998). Spirituality is variously

described as a complex phenomena (Reed 1992) requiring meaning and clarity (Bradshaw 1994). It is most often perceived as a dimension that permeates and interacts with all the other dimensions of a individual (Narayansamy 1995; McSherry and Draper 1998). Dyson et al (1997) identified seven themes from the nursing literature on the meaning of spirituality. These were 'religion and spirituality', 'self others and God', 'meaning' (the quest to finding a meaning in life), 'hope', 'relatedness/connectedness', 'beliefs', and 'expressions of spirituality'. The authors proposed that these themes could be used as framework by nurses for exploring spirituality with the main category 'self, others and God' and the relationship between them. Within this overall framework, the other themes can be articulated.

The research into the nurse's role in delivering spiritual care tends to suggest that nurses are poor at assessing and managing spiritual care. Moreover, some studies have identified that palliative nurses are better than other nursing specialities, including cancer nurses, at identifying and responding to spiritual needs (Stiles 1994; Taylor, Highfield and Amenta 1999). This is not altogether surprising when it is considered that palliative nurses choose to work with death and dying and tend to have spiritual and religious faith themselves. A significant factor in determining the palliative nurses' ability to provide effective spiritual care to dying patients was the nurses' perception of- and awareness of- his/her own spirituality (Sellers and Haag 1998; Taylor et al 1999).

Interestingly, despite the anecdotal evidence that nurses in palliative care provide good psychosocial care and communicate better than nurses in other care settings, there is a lack of empirical evidence to substantiate these claims. However, there is evidence that to suggest that nurses recognise the importance of providing spiritual care to dying patients and that palliative nurses are better at providing spiritual care, than nurses in other care settings.

2.3.6 The nurse's role in providing pain and symptom control

Given that another aspect of the role of the palliative nurse is to provide pain and symptom control to dying patients it seems pertinent to explore the literature in this area.

The importance of the role of pain and symptom control in specialist palliative care is widely held (Quint Benoliel 1988; Higginson et al 1990; WHO 1990; Webber 1993; NCHSPCS 1995: Addington-Hall, Lay, Altmann, McCarthy 1995; Corner 1996; Dunlop and Hockley 1998). Indeed, a systematic literature review quantifying the trends of palliative nursing research over a 10-year period (Wilkes 1998) indicated that an increasing number of nurses are researching aspects of pain and symptom control.

However the contribution of nurses is less clear-cut. Indeed, no studies were identified which explicitly explored nurses' perceptions of this aspect of their role. This is despite the fact that it has been identified that palliative nurses perceived this to be an important area, in terms of priorities for clinical research in palliative care (Cawley and Webber 1995). In order to explore the role of nurses in palliative care delivery in more depth, Lowden (1998) conducted more focused work into the results of Cawley and Webber's Delphi study (1995). They found that pain and symptom control was the largest clinical determinant by both nurses and doctors for initiating palliative care for patients.

No studies have explored how nurses, other health professionals, or patients perceive this aspect of the palliative nurses' role, despite the growing number of nurses initiating and directing studies into aspects of pain and symptom control, indicating the need for further research in this area.

2.3.7 Summary

The preceding literature has identified that the nurse's role in palliative care is multifaceted with most studies centering on the caring and communication aspects of the nurse's role. What may distinguish palliative nurses from nurses in other care setting is their ability to provide holistic care, including psychological, spiritual care and family centred care. Although holistic care may be the panacea for nurses in all care settings, it appears that in palliative care, nurses see the non-physical aspects of their role as the most important. The nurse-patient relationship appears to be key to this role and nurses acknowledge that this is fundamental to their caring practice. However, the evidence base is often weak, particularly in terms of comparing nurses across care settings, exploring what motivates nurses in palliative care and how they

cope with facing death on a day to day basis. In addition, although pain and symptom control is a major aspect of palliative care practice the evidence for how nurses perceive and exercise this aspect of their role is weak.

Although the methodology used to explore the role of the nurse is wide ranging, the majority of studies used a qualitative research design. Most used a small-scale exploratory design, and some demonstrated major methodological flaws such as bias. An exploration of the differences between nurses' and patients' perceptions of palliative care would therefore provide new insights into the subject of palliative nursing.

2.4 Comparing patients' and nurses' perceptions of the role of the nurse in palliative care

The few studies that have been conducted into the difference between nurses' and patients' perceptions of their care have tended to argue that are more discrepancies than similarities into the ways that patients and nurses view nursing care, particularly in the areas of the perceptions of pain and symptom distress (Camp 1988; Sutcliffe-Chidgey and Holmes 1996).

Furthermore, Webb and Hope (1995) have argued that there is by no means a consensus between staff and patients about what is important to patients. They propose that many writers appear to have paid little or no attention to consulting patients, preferring instead to promote modes of practice that professionals judge to be most important.

They are few studies that have compared patients' and nurses' perceptions of the role of the palliative nurse. The exceptions are mainly exploratory, descriptive studies conducted in one setting.

For instance, in an exploratory study conducted in Kansas, Masters and Shontz (1989) aimed to ascertain whether primary care-givers and hospice nurses identified the same problems and strengths in their care as the patients themselves. Using a descriptive research design, data were collected using a 27-item modified Q-sort from 20 patients, 20 care-givers and eight registered nurses. A convenience

sampling technique was used. The Q-sort was based on a review of the literature related to hospice and quality of life. The instrument comprised four headings- 'performance', 'attitudes and affective states', 'well being' and 'support', and 27 sub-items. Data were analysed using inferential statistics.

The results showed that there were no significant differences among means on the total instrument (F=4.19 df =2, p=0.2), indicating that ratings were fairly consistent among nurses, patients and care-givers. Specific items that were significant were 'care for personal needs', with patients and care-givers rating the item as a strength, and nurses rating the item as a problem. Another item, 'fear and anxiety' (F=3.67 df =2, p=0.03), patients rated as a strength while nurses and care-givers rated it as a problem.

Expanding on the issue of exploring nursing behaviours in the care of the dying patient, Maher (1989) conducted a descriptive survey in the U.S.A. in order to assess the perceptions of supportive nursing behaviours by terminally ill patients and hospice nurses. A convenience sample of 20 adult patients and 12 nurses completed the specifically-designed Supportive Nursing Behaviours Scale (SNBS), which was tested for reliability and validity, and a demographic data form. Data were collected in the patients' homes or the hospice in-patient unit, and analysed using inferential statistics. A comparison of the two groups using the Mann-Whitney U test revealed no statistical significance (U-70 p=.053). There was, however a difference in the mean ranks of the scores of patients and nurses. This indicated that patients perceived supportive nursing behaviours as more important than the nurses.

Similarly, in a small-scale study which used a convenience sampling technique with a multiple case study research design, Bergen (1992) evaluated the care of terminally ill people in the community of one health authority in London, England. The data collection instruments consisted of three interview schedules and a supplementary questionnaire related to standard setting. Data were collected from nine patients, nine district nurses and nine Macmillan nurses. Data were analysed using content analysis.

The findings were divided into structure, process and outcome criteria. A major concern for both nurse and patient was related to the lack of adequate pain control. This was previously argued in the studies of Parkes (1985) and Kindlen (1987). However, there is no mention of how this was rated by nurses and patients and how adequately patients felt their pain had been managed. Morerover, there tended to be more correlation between patients and nurses in the more obvious, easily recognised symptoms, such as pain and constipation than in the more 'hidden' symptoms of tiredness, appetite and sleep problems where patients identified that their needs were not always met. The findings indicate an overall discrepancy between patient need and nurse management of that need, particularly in the area of emotional support for carers and management of some symptoms such as fatigue and tiredness.

By using a case study approach as a research design this study obviated the problem of establishing external validity for the small sample, given that generalisation was to theoretical propositions rather than to populations (Yin 1994). Limitations are the fact that the standard used as an interview format tended to be nurse orientated, with needs normatively defined. In addition, adaptations for the three types of respondents meant that categories were not strictly comparable across the groups and, outcome criteria were difficult from a consumer viewpoint, to measure and establish.

In another study comparing patients' and nurses' views of palliative nurses, Cox, et al (1993) focused on descriptive accounts of one Macmillan nurse's work, provided by key individuals coming into contact with this specialist professional service. The study used a case study research design. Data were collected using the critical incident technique (CIT), in an effort to use a method that was neither unstructured nor too highly structured. The study was carried out in London and the sample consisted of five carers, five district nurses, two GPs and eight patients. Data were analysed using inductive classification of the information into categories according to the CIT method.

The findings indicated 12 themes related to positive aspects of the nurse's role and nine themes related to negative aspects of the nurse's role. Positive themes, which were universally acknowledged, were 'specialist knowledge in terminal care',

'provision of psychosocial care' and 'being available'. No negative themes were universally acknowledged.

The CIT as a data collection tool provided a useful method for exploring the positive and negative aspects of the palliative nurse's role. A limitation was the fact that only one Macmillan nurse's caseload was investigated. Exploring the views of the views of patients and other care-givers regarding other Macmillan nurses may well have yielded different findings. Furthermore, further investigation is warranted into patients' views regarding the personal characteristics of the nurse.

2.4.1 Summary

Current knowledge therefore shows that there is a small evidence base regarding comparisons of nurse and patient perceptions of palliative care. The differences in the perceptions of nurses and patients regarding their care are evident, particularly in the areas of fear and anxiety, the need for support for patients themselves and their carers, and the management of pain and symptom control.

Key issues to emanate from the literature are that all the studies lack an in-depth exploration of these notions and neglect to examine the totality of the patients' experience of their care. Although some of the studies investigated the positive and negative aspects of the patients dying experience, more could have been made of an in-depth exploration of these issues, particularly in relation to the patients' views of their palliative nursing care.

2.5 Caring and nursing

The link between caring and nursing is not new. Indeed, past nursing papers have explored the concept of caring in the form of extensive literature reviews, for instance, (Morse, Bottorff, Neander and Solberg 1991; Jacono 1993; Kyle 1995; Smith 1995; Webb 1996; Lea and Watson 1996; McCance, McKenna and Boore 1997; and Sourial 1997) as well as historical analyses (Maggs 1996). Several nurses have devised theories of caring (Leininger 1984; Roach 1991; Boykin and Schoenhofer 1993 and Watson 1988; 1999). Likewise, various empirical studies have been conducted on the nature of caring in nursing (see table 4).

Caring is therefore emerging as a significant concept for the nursing profession. Indeed, the paper by McFarlane (1976) argued that nursing is 'virtually synonymous with caring' (p.189). She asserted that caring consists of 'helping and assisting with daily living activities which may be simple or complex' (p.187). Leininger, another well known nursing writer on the concept of caring, maintained that caring was both the essence of nursing and the central dominant and unifying feature in nursing (Leininger 1984). Likewise, Watson (1999) argued that the practice of caring is central to nursing.

However, although the link between caring and nursing has met with almost universal acceptance, it has received little critical comment. Morse et al (1991) argued that if caring really is the essence of nursing then it must be demonstrated and not simply proclaimed. Crowden (1994) further proposed that the concept of caring cannot be hijacked by nursing or considered a paradigm unique to nursing. Phillips (1996) also dissented from the popular notion of caring as synonymous with nursing by asserting that it was both 'pervasive' and 'erroneous' to hold this view, a notion also asserted by Warelow (1996). However, Lea and Watson (1996) argued that caring and nursing defy precise description and that this undoubtedly contributes to the difficulties in explicating the relationship between them.

Morse et al (1991) provided a systematic review exploring the concept and theoretical perspectives of nursing and caring. They grouped caring studies under five conceptualisations of caring- 'caring as a human trait', 'caring as a moral imperative', 'caring as an affect', 'caring as an interpersonal interaction' and 'caring as a therapeutic intervention'. Their review highlights the diversity of conceptualisations of caring in nursing. They argued that there remains a loose link between definitions of caring and patient outcomes. They maintained that there is a controversy concerning whether caring can be reduced to a set of behavioural tasks and the underdeveloped links to specific outcomes. They claimed that these form the 'Achilles' heel of caring theory. They also indicated the need for theoretical preciseness, clarity and parsimony when describing complex concepts.

The spectrum of epistemological argument about the nature of caring in nursing is reflected in the research methods that are applied to its study. For instance, those

researchers that take an existential view of caring in nursing tend to rely on qualitative methods (Benner and Wrubel 1989; Forrest 1989). There are, however, investigators who do not view caring existentially, who operationalise caring variables in order to quantify them or study them using direct observation, such as Von-Essen and Sjoden (1991). Morse et al (1991) argued that there is room for further exploration on the concept of caring. They particularly endorse the notion of developing caring theories inductively from qualitative data.

There are, however, common themes in the studies into the link between nursing and caring, despite the different epistemological and methodological approaches used in caring research. These are aspects of interpersonal interaction, the nurse having personal and professional attitudes and values and aspects of doing for, or physical intervention.

While such expressions of caring appear to capture the essence of caring, particularly in nursing, the interpretation, and translation of the notion of caring into nursing practice remains contentious. This may be due to how caring is constructed and located within the structure of the nurse-patient relationship. In addition, the essence of caring as a concept may be undervalued, with caring activities seen as low level, basic aspects of nursing practice.

A limited number of studies have assessed nurses' perceptions of their caring role (see table 4). As well as patients' perceptions of the nurses' caring role (see table 4). Studies which compared nurses' and patients' views of their care were scarce.

Current knowledge into nurses' perceptions of their caring role therefore indicates that they perceive that the role is multi-faceted with interactive aspects of the nurse-patient relationship predominating, such as being there, listening to the patient, information giving, establishing trust. Aspects of giving support and choice regarding care were also seen as important, as well as physical aspects of caring, such as giving comfort. On the other hand, nurses perceived the negative aspects of their care as lack of time, environmental and institutional issues suck as lack of resources, lack of support from peers and managers, and pressure in work.

This contrasts directly with the findings of the few studies to ascertain how patients perceived the nurse's caring role which mainly involved physical rather than interactive or emotional elements, such as knowing when to call the doctor, and knowing how to give physical care. Patients also indicated that important aspects of the nurses caring role involved spending time with them and being there for them.

These differences have highlighted the importance of ascertaining both patients' and nurses' views regarding the concept of caring and caring characteristics. This is particularly important in the care of the dying, where the shift from curative treatment to palliative care means that the aim of care is not to cure, but to maximise the quality of living and dying for patients and their families.

Table 4 Aspects of caring identified in research studies related to the nurses' caring role.

NURSES' PERCEPTIONS OF THEIR CARING ROLE	PATIENTS' PERCEPTIONS OF THEIR CARING ROLE	METHODOLOGY	SAMPLE SIZE	SPECIALITY	AUTHOR
Involvement e.g. being there, respect, closeness, Interacting; Oneself; e.g. own experiences, beliefs, self-appraisal, The patient e.g. hard to care for the patient, what patients tell you Frustrations; e.g. lack of time, nurse administrators, fellow nurses, physical environment, Coping; Comfort and Support		Phenomenology	17 Nurses	Medicine, surgery, psychiatry and paediatrics	Forrest 1989
Personal qualities Clinical work style Interpersonal approach Level of motivation Concern for others Use of time Attitudes		Repertory Grids	25 Nurses	General nurses	Morrison 1989,1991
Listens to the patient (comforts)	Knows when to call the doctor	CARE-Q instrument	81 Patients 105 Nurses	Oncology, general, orthopaedic and surgical	Von- Essen and Sjoden 1991
Listens to the patient (comforts)		CARE-Q instrument	110 Nurses		Komorita, Doehring and Hirchert 1991
Being Supportive		Phenomenology	6 Nurses	Medicine, urology and	Clarke and Wheeler 1992

Communicating Pressure Caring ability				surgery	
Listens to the patient	Listens to the patient	CARE-Q instrument	61 Patients 63 Nurses	Psychiatric	Von-Essen and Sjoden 1993
Translating- e.g. informing Getting to know you Establishing trust Going the extra mile		Ethnography	40 Patients 12 Nurses	Orthopaedic, chest medicine, cardiology	Fosbinder 1994
	Attributes of the nurse e.g. understanding, genuineness Giving emotional support Giving physical support	Descriptive multiple case study design	5 Patients	Nursing Home	Poole and Rowat 1994
Gentle humour Physical comforts Providing information Emotionally supportive statements Choices regarding care Social exchange Increasing proximity Touch		Qualitative ethnology-videotaping	8 Patients 32 Nurses	Oncology	Bottorff, Gogag, Engleberg-Lotzhar 1995
	Knows how to give shots, IVs e.t.c (monitors and follows thorough)	CARE-Q instrument	57 Patients	Oncology	Larson 1995
Consideration and Sensitivity Giving of self Work Style Motivation Communication and Meeting needs Knowledge and Learning Individual approach General approach of the		Repertory Grid Technique	9 nurses	Variety of general hospital acute settings	Dyson 1996

person Honesty and Sincerity					
	Being with e.g. connecting, Sharing humanness, Integrating services Being technical Doing to and for Spending Time	Phenomenology	6 Patients 14 Nurses	Neurology, chest surgery	Milne and McWilliam 1996
Tempering involvement Doing the right thing Cleaning up Weaving a fabric of moral meaning		Naturalistic Inquiry	9 Nurses	General Nurses	Maeve 1998
Personality characteristics e.g. kind-unkind Physical caring activities e.g. touch-impersonal Psychological caring activities e.g. communicative-reserved	Patients most commonly used constructs Knowledgeable-ignorant Patience-impatient Helpful-unhelpful Kind-cruel Thoughtful-thoughtless Pleasant-unpleasant Interested-disinterested Gentle-rough	Repertory Grid Technique	10 Nurses 10 Patients	Nursing Home	Ellis 1999

2.5.1 Summary

Caring is therefore a more complex phenomenon in nursing than might be immediately apparent. It follows that if there are differences between nurses' and patients' perceptions then practitioners should not make assumptions about care and caring. Furthermore, an investigation into aspects of caring would be more complete if both nurse and patient views were sought.

It is generally agreed that caring, as an entity, cannot, in the strictest sense, be measured. There appear also to be two main components of caring in nursing the instrumental, or physical, component of care or 'doing for', and the expressive element or affective component of care. Both nurses and patients have identified these two components of the caring role. Although nurses tend to perceive that the expressive role is more important than patients. It therefore serves that further exploration of nurses' and patients' perceptions of palliative caring and what they perceive to be positive and negative characteristics of the palliative nurse's caring role is required. Although the literature review identified that both qualitative and quantitative methods are useful for studying caring, a complete and deeper insight of the issue may be apparent when a mixed method is used.

2.6 Conceptualisation of the dying experience

The dying experience has been researched for 30-35 years and there have been several theories of dying put forward during this time (Glaser and Strauss 1965, 1968; Kübler-Ross 1969; Pattison 1977; Corr 1991-1992; Buckman 1992; 1996, 1999; Copp 1996). Central to the theories put forward during the 1960's and 1970's is their focus on situations in practice, and in particular death and dying in institutions. Furthermore, the majority of these theories focused on the perspective of health care professionals regarding death and dying and ignored the patients' viewpoint.

Glaser and Strauss (1965; 1968) conducted one of the earliest studies into the experiences of dying patients. Glaser and Strauss's research is considered seminal because it was the first study to explore the issue of communication with dying patients, the impact of their work paved the way in both clinical and academic

practice for the discussion of communication with the dying. In particular the work provided the start of the modern approach to discuss, research, and plan protocols in relation to the disclosure of bad news to dying patients. In addition, Glaser and Strauss conceived a new qualitative methodology, which they termed grounded theory, which has had a significant influence on health care and social science research.

Glaser and Strauss conducted a grounded theory study with patients and health care professionals in six acute hospitals in San Francisco. They identified a number of patterns of dying or dying trajectories that influenced the way that patients responded to dying. The four different types of dying pattern identified were 'certain death at a known time', 'certain death at an unknown time', 'uncertain death but at a known time when certainty will be established' and 'uncertain death at an unknown time when the question will be resolved'. Deaths were also theorised as 'lingering', 'expected quick' and 'unexpected quick'. 'Certain death at a known time' is more commonly known as sudden death and is experienced by those suffering trauma or accident. Stedeford (1994) claimed that, with this type of death, there may be no pain and little evidence of emotional distress. Controversially, those who have experienced near-death experiences describe a detachment from the moment of trauma, often telling of a pleasant journey following a light or benevolent figure. After their recovery, they are less afraid than before (Stedeford 1994).

'Certain death at an unknown time' is the dying trajectory most commonly associated with a life threatening illness such as cancer. Here, the individual adopts coping strategies individual to them and adapts to their situation. They may experience a range of emotional reactions at this time. On the other hand those patients who experience 'uncertain death at a known time' tend to have chronic disease such as chronic heart disease awaiting a cure in the form of a transplant. Throughout the course of their illness, the patient may accept that, without surgery, the probability is that that they will die in the foreseeable future. The 'uncertain death at an unknown time' affects those with a lingering chronic illness where the death is not expected in the near future but the chance of a complete cure is remote.

The common theme here is the difficulty for the individual to remain in control: stress may, therefore, predominate.

There is much strength to Glaser and Strauss's theory. Authors such as Lindley-Davis (1991), Honeybun, Johnston, Tookman (1992) and Pilsworth (1994) have also argued that the dying process can be conceptualised as a journey. In addition, researchers such as Hutchinson, Leger-Krall, Wilson (1997), Seale, Addington-Hall, McCarthy (1997) and Hyde (1998) have extended Glaser and Strauss's work on awareness contexts. The differing dying trajectories can also offer care-givers an insight into how they can enable patients and their families to cope with their situation and facilitate appropriate interventions. Moreover, Glaser and Strauss also found that staff interaction with patients was closely related to the expectations that had formed about time and certainty of death. Researchers such as Rando (1984), Wright (1985), Wilkinson (1991) and Faulkner and Maguire (1994) have also asserted this. Rando argued that, because the dying trajectories contain expectations about certainty and time of death, they can give everyone involved guidelines for responding and interacting with the dying person.

There are, however, limitations to this theory. Health care professionals may compartmentalise individuals and misinterpret their reactions and forget the individuality of the person's experience. The research was also conducted in one area of the United States in the early 1960s and much is different in current health care practice in the U.K., both in terms of the organisation of care and the emergence of death and dying as a clinical speciality. Moreover, the theories lack microanalysis of several key issues. The major themes are postulated at a descriptive level so that there are few attempts to deepen the credibility of some of the hypotheses presented (Copp 1998). In addition, Glaser and Strauss do not describe their sample size, sampling technique or methods of analysis. While it is stated that comparison groups were utilised to maximise differences and similarities, they do not describe what these groups were or how these comparisons were undertaken.

One of the other notable researchers to investigate the dying experience was Elizabeth Kübler-Ross (1969). As a psychiatrist, she observed and interviewed

dying patients as part of her clinical practice and teaching role and was one of the first researchers to conceptualise the process of dying. She interpreted it as five consecutive stages- denial, anger, bargaining, depression and acceptance.

This particular theory has received considerable professional and public attention and has been utilised widely, not only as a model for dying but also a model for grief. It is still, arguably, the main piece of work that has encouraged sociologists, psychologists, doctors and nurses to study death and dying. Its influence on how health care professionals care for dying patients is, therefore, significant.

However, Kübler- Ross's work has been criticised (Sims 1988; Corr 1993; Kastenbaum 1995; Buckman 1999), in particular for the fact that the stages do not allow for the individual and dynamic nature of the dying experience (Kastenbaum 1995). The five stages also give the impression that if patients do not respond in the sequence Kübler-Ross (1969) suggested, then there is something wrong with their coping strategy (Buckman 1999). Human emotions are not serial and universal, but idiosyncratic and simultaneous. Individuals react to the news that they have a serious illness with different reactions and different coping strategies. They utilise coping strategies that are characteristic to them and the way that they have reacted to events in the past, (Sims 1988; Kastenbaum 1995; Buckman 1999).

Further to these paradigmatic flaws with Kübler-Ross's (1969) five stage response to dying is the omission of other emotions which are frequently experienced by the terminally ill person. Fear is one such example. Numerous authors such as Weisman (1979), Rando (1984) and Kalish (1988) have maintained that terminally ill patients have numerous fears related to their illness and their impending death. Moreover, guilt and shame are also frequently associated with illness and, especially, with a terminal illness. Rando (1984) argued that guilt arises when people behave contrary to their ethical and moral principles and their self image is questioned, and when they fear their illness as a punishment.

The terminally ill person may also experience hope and hopelessness (Herth 1990; Yates 1993; Flemming 1997). Indeed, Fromm (1968) and Frankl (1987) argued that

hope is necessary for survival. Another emotion that may be experienced by the dying individual, employed as a coping strategy- and often understated- is humour (Herth 1990; Perry 1996; Buckman 1999). There is also no evidence in Kübler-Ross's theory for the need of dying patients to maintain and preserve their independence and control (Rando 1984; Kastenbaum 1995), a vital part of coping with a life threatening illness (Flanagan and Holmes 1999).

Moreover, Kastenbaum (1995) argued that there is no empirical evidence for the existence of Kübler-Ross's (1969) five stages, and that her work has never been replicated or validated. Likewise, her research design and methodology were not rigorous or clearly identified. Her theory was based on psychiatric-type interviews conducted as part of her clinical practice and in the presence of medical and theology students. Her interpretative process was also not subjected to the rigour of a methodological or theoretical paradigm. Additionally, Corr (1993) argued that an adequate model for coping with dying should be as agile, malleable and dynamic as the behaviour of the individual dying patient. The model or theory should therefore respect individuality as well as universality, and offer practical guidelines for care givers.

Pattison (1977) proffered the 'Living-Dying interval' model to understand the process of dying. His work drew on both psychodynamic and humanistic theories. He divided the period of 'living-dying' into three clinical phases- the 'acute crisis phase', the 'chronic living-dying phase' and the 'terminal phase'. He stated that individuals cannot intervene with the ultimate problem of death, but can respond to the acute crisis, so that it does not result in a chaotic disintegration of the person's life during the process of dying. He asserted that the first task of professionals and family members is, therefore, to deal appropriately with the crisis of knowledge of death so that the dying person can move into an appropriate trajectory that integrates his or her dying with their lifestyle and life circumstances. The carer can do this by focusing on reality issues and providing emotional support so that the dying person can express appropriate emotional responses. He described these emotional responses as 'pathological defence mechanisms' which he likened to the phases of Kübler-Ross (1969) such as 'denial', 'anger' and 'bargaining'. The second task was

to respond to the adaptive issue of the chronic phase. Pattison maintained that, in this phase, the dying patient faces a number of fears. The carer's role is to take each fear separately and enable the dying person to resolve it in a way that enhances self-esteem, dignity and integrity. He termed this 'healthy dying'. Finally, the third task was to assist the patient to move easily into the terminal phase, when appropriate. Pattison suggested that the terminal phase occurred when the dying person begins to withdraw into him or herself in response to internal body signals. This can be likened to the work of Hinton (1972), who proposed that the terminal phase was characterised by a decrease in anxiety and an increase in depressive involution. Wright (1985) further argued that the terminal phase begins when the dying individual starts to turn from the outside world and withdraws into the internal self. She maintained, like Pattison, that this was a bodily reaction which signals that energy is to be conserved. However, authors of studies on interpersonal communication such as Faulkner and Maguire (1994) asserted that dealing with a withdrawn patient is a problem or challenge.

Strengths of Pattison's theory are the fact that it takes into account the need for integrating dying according to the pace, emotions and reactions of the dying patient. It, therefore, relates directly and meaningfully to clinical experiences. Limitations of this theory are the assumption that the process of dying is always a downward trend.

In this researchers' experience, however, not all patients view death as a negative experience. Some patients believe their life is enhanced by the introspection that facing death gives them. Certain patients may even feel more spiritually aware and more motivated to try new activities or fulfil goals. Patients sometimes even talk of facing death as enhancing their life.

Following on from Pattison's notion of accomplishing tasks in order to help the person who is dying, Corr (1991-1992) postulated his theory on the task-based approach to dying. The lack of material on dying theories in the 1980s may in part be due to the fact that this period was dominated with studies on coping with bereavement rather than dying (Parkes 1986; Stroebe and Stroebe 1987; Worden 1991).

Corr's theory uses two central concepts- 'tasks' and 'coping with dying'. Corr proposed that people facing dying carry out four tasks in four key areas to cope with dying. The first key area was physical, which involved satisfying bodily needs and minimising physical distress in ways that are consistent with their personal values. The second task covered the psychological domain and involved maximising psychological security, autonomy and richness of living. The third area entailed social issues and comprised sustaining and enhancing interpersonal attachments of significance to the person and addressing social implications of dying. The fourth, and final, task consisted of spiritual issues and involved the need to identify, develop and reaffirm sources of spiritual energy and, in so doing, fostering hope.

Although Corr postulates a task-based theory, he argued that his tasks operate from the perspective of individuals and their coping tasks. This is in direct contrast to bereavement task based models such as Worden (1991), who suggested that bereaved individuals need to accomplish all four of his tasks in order to complete their grief work. Corr further implied that coping with dying takes various forms with various outcomes. He was influenced in his thinking by the work of Weisman (1979) and Lazarus and Folkman (1984). He proposed that coping encompasses more than reacting to, or defending against, the events and challenges of life and that it involves an awareness of events and challenges with efforts to contend with them. Another tenet to Corr's theory is the realisation that dying affects not only the individual but also their families, friends and carers. Corr argued that any model for dying should contribute to improved understanding, empowerment, participation, and guidance for helpers to cope with dying.

Although Corr proffered the notion of a task-based approach to coping with dying as a novel concept, this idea is not new. Indeed, preparation for death, 'getting one's affairs in order' and making provision for family members is an important feature of modern society (Kellehear 1990; Walter 1994). Furthermore, more in-depth analysis is needed into the tasks and sub-tasks related to coping, such as the relationship between dying and tasks and the nature and extent to which tasks might differ during dying as opposed to those encountered during everyday life (Weisman 1992).

Likewise, the absence of empirical data to support Corr's assertions weakens the impact of this model.

Buckman (1992; 1996; 1999) attempted to take on board the weaknesses of previous dying theories and devised a model which represents the individual, dynamic nature of the dying person's ability to cope with his/her illness. His model is based on two central propositions that 'patients exhibit a mixture of reactions and responses characteristic of the patient and not the diagnosis or stage of the dying process', and that 'progress is marked by resolution of resolvable elements of these emotions'. The model comprised three stages- 'initial stage', 'chronic stage' and 'final stage'. The initial stage involved facing the threat and a mixture of reactions which are characteristic of the individual and which may elicit a number of emotional reactions. The chronic stage consisted of resolution of these elements of the initial response, which are resolvable. The final stage involved acceptance, defined by the patient's acceptance of their death.

A weakness of Buckman's theory is that, firstly, it was devised from Buckman's considerable clinical experience as a physician rather than a particular rigorous research study. Moreover, although Buckman acknowledged that not every person will reach acceptance, he still perpetuated the myth that acceptance is the panacea for all terminally ill people. Some people will not accept that they are terminally ill or that they are dying; they will, instead, cope in the way that they have coped with traumas in the past.

Copp (1996; 1997), in her PhD study, enlarged on previous theorists, particularly Corr's work. She extended the notion of the multifaceted nature of death and its impact on dying people and their carers. Copp conducted a qualitative study, drawing on a symbolic-interactionist theoretical perspective. The purpose of the study was to explore patients' construction and management of their experiences in confronting their impending death and the nurses' experiences in caring for the individuals as they died. The study was conducted in one NHS hospice in England. Data were collected using unstructured interviews and participant observation from 12 hospice patients and 15 registered nurses using a convenience sampling

technique. Multiple interviews were conducted with all participants. These ranged from four to 16 interviews with each participant. Data were analysed using a constant comparative grounded theory approach (Strauss and Corbin 1998). Common patterns of dying were identified and grouped together as main core categories and sub-categories.

In total, 12 main categories and 40 sub-categories were generated from the data. These consisted of 'progression of bodily deterioration', 'exercising control', 'constructing death', 'protecting', 'treatment experience' and 'family relationships'. In addition, Copp postulated a new theory for dying which she developed from the patients' and nurses' constructions of death. She identified four modes of dying- 'person ready, body not ready', 'person ready, body ready', 'person not ready, body ready', 'person not ready, body not ready'. She argued that the shape, duration, expressions and manner of dying define these patterns. An individual patient could exist in one pattern or mode at a time, but could also change between modes depending on the physical condition of their body and also their acceptance of the imminence of their death.

Although Copp's theory is novel, particularly as it is the only dying theory to include a nursing perspective, it can be likened to Lawler's (1991) PhD study that proposed a style of nursing practice which integrated lived experience with the object body. However, Copp is one of the only dying theorists to incorporate the physical component of dying. She is also one of the only British researchers to combine patient and nurse accounts of the process of dying. In addition, the body-person split and 'readiness to die' constructions provide an additional dimension to current theoretical conceptualisations about the dying process. Previous theorists such as Glaser and Strauss (1965, 1968), Kübler-Ross (1969), and Pattison (1977) have tended to focus on the notion of individuals' reactions to the process of dying, their awareness of dying and the time and duration of dying.

A limitation of the study is the fact that the study was carried out in only one hospice, where the author worked at the time. The criticism of bias could, therefore, be levied. In addition, all the patients in the study had cancer. It would have been

helpful to include patients with non-malignant progressive disease, who may have had different perceptions about the process of dying. Copp also overcomplicates the description of her research design and methods. Although she justified her choice of symbolic-interactionism as an interpretative framework, this author believes that the study lends itself to phenomenology as an interpretative framework. The notion of lived experience of participants, and the fact that Copp conducted multiple interviews with participants, fits within the notion of a phenomenological approach.

2.6.1 Summary

Current knowledge indicates that the process of dying is characterised by an individual patient's ability to cope with and adapt to their illness. This process is distinguished by their reactions and responses to their impending death and the resolution of these factors. The majority of theories consist of stages, phases, or tasks, which are predominately psychosocial in nature. Fewer theories have taken on board the holistic nature of the process of dying and incorporated a physical response in the form of body deterioration. Moreover, most dying theories have not taken account of the dynamic, individual nature of dying and the spiritual reaction which patients may exhibit.

None of the theoretical approaches to dying discussed, apart from Copp (1996), takes full account of the dying individual's physical condition. Likewise, none of the approaches, apart from Copp (1996), account for the dying person's own perspective and values. This has limited the understanding of the individual manner and styles of dying. Glaser and Strauss (1965; 1968) were the only authors to concentrate on the interaction approaches or awareness of dying, an area that requires further investigation. Furthermore, Copp (1998) and Corr (1991-1992) are the only two theorists to incorporate the role of the health professional in the dying process and their encounters with dying patients. This is another area which requires further investigation, particularly in relation to the impact of dying on nurses, and how they view the care of the dying person. Another area requiring further investigation is the impact of the dying experience on carers.

2.7 Overall summary

The literature review has analysed studies in the areas of: the meaning of a 'good death, patients' perceptions of palliative care, nurses' perceptions of palliative care, the difference between nurse' and patients' perceptions of palliative nursing, caring and nursing' and conceptualisations of the dying experience. The following problems were identified from the literature. Very few authors have explored the experience of dying from the perspective of patients (section 2.1, section 2.2.3). None have explored the dying experience with patients who are dying from non-malignant disease as well as cancer (section 2.2). Very few studies have asked dying patients for their views of their care, and in particular, their nursing care (section 2.2). None of these studies compared the experience of dying patients across different care settings. Few studies compared dying patients' and nurses' views of palliative nursing (section 2.4). Moreover, these all had methodological flaws and were mainly small-scale studies, conducted in one setting. Only one study explored the positive and negative experiences of patient care, and that study was specifically exploring patient views of a Macmillan nurse role (section 2.2). The studies conducted into patients' experiences of hospice care, tended to be in the form of patient satisfaction research, asked structured questions set against pre-determined criteria and evaluated the care at only one hospice. Bias and lack of generalisability, therefore predominated these studies (section 2.2.2). No studies identified in the review explored the lived experience of the dying patient receiving palliative care in a hospice or hospital or explored patients' views of the nurse's role in controlling pain and symptoms or providing psychosocial care (section 2.2.4, section 2.2.5).

Only three previous studies have explored the concept of the good nurse in palliative care. These were all conducted in single institutions. They were all North American studies and none approached patients for their views of a good palliative nurse (section 2.3.1). The few studies that have explore palliative nurses' perceptions of their care, tended to be small-scale, descriptive studies, conducted in one setting and mainly North American (section 2.3.2). They also mainly explored the clinical nurse specialists' perceptions of their role. The few studies to explicitly explore the role of the hospice nurse were all North American, small-scale, descriptive research studies (section 2.3.3).

There is little evidence of the impact of death and dying on nurses and how they cope with death and dying, when working in palliative care (section 2.3.4). No studies have explicitly explored how palliative nurses perceive their role in providing pain and symptom control or psychosocial care (section 2.3.5, section 2.3.6). No studies have explored the characteristics of caring in palliative care and the differences between how nurses and patients perceive the characteristics of caring (section 2.5). Few studies have explored the experience of dying from the perspective of patients (section 2.6). Only one study explored the dying experience of both patients and nurses and the focus of that study was how patients face death, and the nurses response to caring for them (section 2.6).

The following pointers identified from the literature review are included in this study. As a large number of the studies reduced their generalisability by being conducted in only one setting, it was decided to recruit informants from more than one site for this study (section 2.2, section 2.3, section 2.3.1). In addition, there is evidence that family and patient perceptions of their care are different, and that patients may give different responses if their family members are present when they are being interviewed (section 2.2.6). It was therefore decided to interview patients alone for the main study. As no previous studies exploring patients' perceptions of their palliative care have included patients with non-malignant as well as malignant disease, it was decided to include both groups of patients in this study, in order to get a fuller picture of patients lived experience of their terminal illness (see Chapter 4 for a fuller explanation of these issues).

Following the review of the literature and the identification of problems, the aims and research questions were devised as follows.

2.8 Study aims

2.8.1 Overall study aim

The aim of the research was to investigate the role of the nurse in palliative care.

2.8.2 Aims of the study

1. To explore the concept of the good nurse in palliative care.
2. To discover how nurses perceive good and bad palliative care.
3. To discover how dying patients perceive good and bad palliative care.

2.9 Research questions

The study set out to answer the following questions:

1. What is palliative nursing care from the patient's perspective?
2. What is palliative nursing care from the nurse's perspective?
3. Are there differences between patients' and nurses' perceptions as to what constitutes good palliative nursing care?
4. What do dying patients identify as characteristics of caring?
5. What do nurses caring for dying patients identify as characteristics of caring?

The following chapter explores the literature related to the selected methods for this thesis.

Chapter 3: Literature Pertaining to the Selected Methods

3.0 Introduction

After a review of the literature a decision was taken to use a phenomenological approach with in-depth interviews, supported by repertory grids, within a mixed method approach (methodological triangulation). In this chapter the researcher will explain how these decisions were reached and explore the literature around the methods chosen.

3.1 Methods that could have been used for this study

As has been previously identified from a review of the literature (Chapter Two), a range of approaches have been used by researchers to investigate aspects of death and dying. This diversity reflects the multi-dimensional, as well as complex nature of the problems involved. It is appreciated that there are different ways of exploring nurses' and patients' perceptions of palliative care. Therefore, the range of approaches that could have been used for this study will now be explored, with the problems identified, and the reasons given for not choosing them. The methods chosen for this study are then explored in-depth and the reasons for choosing them demonstrated.

Qualitative research

It was decided early in the course of this study that a study exploring nurses' and dying patients' perception of their care lent itself to a qualitative approach. This is because qualitative research is described as a mode of systematic enquiry, concerned with understanding human beings and the nature of their transactions with themselves and their surroundings (Quint Benoliel 1984). Furthermore, its purpose is to challenge the status quo and to identify new paradigms or directions of inquiry (Morse 1991b). Qualitative research can also offer rich descriptions of what it is like, for instance, to be a patient.

What type of qualitative approach to use, was, however, a more difficult decision, this required a comprehensive exploration of the literature before a conclusion was reached. Qualitative research is divided into two types- descriptive and

interpretative. Interpretative qualitative research is further divided into three main types- ethnography, grounded theory, and phenomenology (Morse 1991b).

Descriptive studies

Descriptive studies aim to observe, describe and document aspects of a situation as it naturally occurs (Polit and Hungler 1999). The goal of qualitative, descriptive studies is a comprehensive summary of events in the everyday terms of those events (Polit and Hungler 1999). Qualitative, descriptive studies are widely used in palliative care. A total of 11 descriptive studies were reviewed in the first part of this chapter. This popularity may be because researchers employing a descriptive design have little knowledge of other qualitative designs. Alternatively, it may be because descriptive studies are typically an eclectic combination of sampling, data collection, data analysis and presentation techniques, and researchers may prefer to use this eclectic combination. In the case of palliative nursing research, however, researchers have tended to use a descriptive design when a more theoretically grounded, interpretative design may have been more appropriate (see section 2.2, section 2.3).

Using a descriptive research approach for this study was therefore rejected for the following reasons. The general view is that descriptive research is a lower level form of qualitative inquiry than other, interpretative, qualitative methods (Sandelowski 2000). In addition, a descriptive approach would not have provided the in-depth exploration the researcher was looking for, to provide a holistic picture of nurses' and patients' experiences of dying. In addition, a descriptive approach would not have fulfilled the objective of having a theoretically grounded study, which hopefully will be more useful to practitioners caring for dying patients.

Ethnography

Ethnography on the other hand, is derived from anthropology and refers to a uniquely humanistic and interpretative approach (Atkinson and Hammersley 1998), involving investigating a group or culture to understand their patterns, lifestyle and behaviour. Ethnography usually involves participant observation, where the researcher participates in peoples' lives for a time, whilst collecting data. Ethnographic research in palliative care is becoming more popular, and four ethnographic studies were

identified in the first part of this review. However, the ethical difficulties and time constraints of conducting participant observation with dying patients and nurses, meant that this methodology was not a suitable consideration for this study.

Grounded theory

Grounded theory is a general, qualitative methodology for developing theory that is grounded in data, systematically gathered and analysed (Strauss and Corbin 1998). A central feature of this interpretative, analytical approach is constant comparative analysis. It was developed by Glaser and Strauss, in their study of communication and awareness of cancer patients (Glaser and Strauss 1967), and is derived from symbolic interactionism. Three studies using grounded theory were reviewed in the first part of this literature review.

It is acknowledged by this researcher that grounded theory is more like phenomenology than the other qualitative methods and thus lends itself to a study of the perceptions of palliative care. They both focus on the richness of human experience, both seek to understand a situation from the participant's frame of reference and both use flexible data collection procedures. However, although it was considered as an approach for this study it was rejected for the following reasons. The emphasis in grounded theory is theory development, and theory development was not the main focus of this study. Likewise, a feature of the theory development aspect of grounded theory involves gathering and reviewing literature after data collection has been completed. This feature of the philosophy of grounded theory did not sit well with this researcher who was uncomfortable about commencing data collection without a review of the literature. Moreover, the early proposals for ethical clearance and funding required the researcher to conduct a literature review. Although, this in itself is not a good enough reason for rejecting grounded theory, it added to the researcher's decision to reject an approach she did not feel she could do justice to if she was compromised in this way. In addition, grounded theorists often use both participant observation and interviews as methods of data collection. It was felt that in-depth interviews were more suitable as a mode of collecting data for this research, in order to allow dying patients and palliative nurses to tell their stories. The strength of grounded theory lies in the systematic asking of, and generating

questions, theoretical sampling and systematic coding. It would, therefore, not have been suitable for an approach which required a specific minimum sample size. In addition, as the nature of grounded theory requires small sample sizes, this researcher felt that adopting too small a sample size would compromise her desire to explore the nature of palliative care across different care settings.

Case studies

Case studies are an in-depth investigation of an individual, group, institution, or other social unit (Polit and Hungler 1999) and have been traditionally popular in medical and nursing research (Polit and Hungler 1999). Case study research may be useful in palliative care, when sample sizes are likely to be small. Five studies reviewed in the first part of Chapter Two, used case study research. Case study research was rejected for this study because problems with case study research include the familiarity of the researcher with the subject matter, which makes bias more common, objectivity more problematic, and generalisability impossible. As a larger sample size (44) was necessary for this study, (Chapter 4 section 4.5) a case study research design was not considered a suitable methodology.

Survey research

Survey research, usually involving questionnaires as a method of collecting data, is designed to obtain information from populations regarding the prevalence, distribution and interrelations of variables within these populations (Polit and Hungler 1999). Moreover, surveys are popular in palliative care research, particularly when evaluating aspects of care, such as patient or relative satisfaction with care (Addington-Hall and McCarthy 2001). In the first part of the literature review, 11 surveys were analysed. An advantage of survey research is its flexibility, broadness of scope and ability to utilise large sample sizes. However, there are a number of limitations of survey research, which made it an inappropriate method for this study. For instance, the information obtained in surveys tends to be relatively superficial. Moreover, questionnaires rarely probe into feelings or contradictions of human behaviour and are therefore unsuitable for an in-depth exploration of dying patients' experiences of their care.

3.2 Phenomenology

The word phenomenology comes from the Greek *phaino* meaning appearance and *logos* meaning reason. Thus, phenomenology is the study of phenomena, the appearance of things (Cohen 1987). Phenomenology attempts to study the human experience as it is lived (Merleau-Ponty 1962). It is often termed, therefore, a study of lived experience (Oiler 1982; Omery 1983; Van Manen 1990; Beck 1994; Holstein and Gulbrium 1994). Its purpose is to seek a fuller understanding through description, reflection and direct awareness of the many facets and integral meanings of a phenomenon (Merleau-Ponty 1962; Oiler 1982; Omery 1983; Cohen 1987).

Omery (1983) described phenomenology as an inductive, descriptive research method. The task of the method is to investigate and describe all phenomena including the human experience in the way those phenomena appear in their fullest breadth and depth (Spiegelberg 1982). The goal of empirical phenomenology is to allow common meanings and underlying empirical variations of a given phenomenon to be determined (Baker, Wuest and Noerager Stern 1992).

The central process within phenomenology is rational and intuitive. This can confound attempts by some researchers to reduce it to a step-by-step method, relying on mechanistic and empirical processes (Hallett 1995). Phenomenology is a paradigm that guides the research process rather than restricts it (Hallett 1995). Furthermore, phenomenological research is a research method that involves an interactive involvement between the researcher and the researched (Bergum 1991). However, it is pointed out that the phenomenological method is often over-simplified or misunderstood (Koch 1995; Walters 1995; Crotty 1996).

A phenomenological perspective as a philosophical and theoretical framework was therefore selected to underpin this study. For the following reasons it looked more sensible. This perspective was chosen as the perception of palliative nursing is a complex and under researched area. Moreover, phenomenology was considered to be the most suitable methodology as this is a study of the lived experience of dying patients and the nurses caring for them. The philosophy of phenomenology also fits with the philosophy of palliative care, in that both are a partnership between

professional or researcher and patients or informants. Both aim to make sense of the experience of illness or dying, and both have a notion that allowing people to tell their stories can be beneficial and even therapeutic (Seymour and Clark 1998). Finally, phenomenology is an appropriate method to answer experiential questions such as 'What does it feel like to be a dying patient? and 'What does it feel like to be a palliative nurse?

3.2.1 Historical development of the phenomenological method

The volume of literature in the North American and British academic nursing press related to the philosophies of Husserl (1964, 1977a 1977b, Heidegger (1962) and Gadamer (1994) has escalated in the last five years. Although the literature is of value, it is often confusing and repetitive, and this has detracted from an understanding of the philosophical underpinnings to phenomenology.

Nursing phenomenology has come in for much comment by philosophers such as Van Manen (1990) and Crotty (1996). Koch (1999), who has contributed much to the debate on using phenomenology as a nursing research method, argued that is it not necessarily important for nurses to understand the work of Husserl, Heidegger and Gadamer. She suggested that it is only worthwhile reading the original German texts selectively under the guidance of a mentor or within a philosophical study programme. Corben (1999) disagreed, asserting that it was necessary for nurse researchers to understand where phenomenology originated. Nevertheless, she conceded that the language used in philosophical texts is difficult to understand for those without a foundation in philosophy. She also perceived this as a potential difficulty, leading to misuse of phenomenology. Literal translations from German have caused concepts to lose the special meaning assigned to them by the philosophers.

Nurses consequently often read about phenomenology from secondary or tertiary sources. This researcher *did* read the original texts translated from the German in order to understand the theoretical underpinnings to this study, extract key issues and make clear the historical development of phenomenology. Reading about phenomenology and becoming immersed in the literature undoubtedly helped the

researcher to reflect on her choice of methodology and gain a deeper understanding of the principal tenets of the methodology. However, struggling through the philosophers' original works probably did little to enhance this process. The researcher tends to agree, therefore, with Koch's (1999) comments that it is not necessarily important for nurses to understand the work of Husserl, Heidegger and Gadamer in order to understand nursing phenomenology.

The use of a phenomenological approach in nursing is, therefore, clearly different to how philosophers would use it. For this reason a section exploring the historical, philosophical thinking behind phenomenology has been omitted. For a review of the of Husserl, Heidegger and Gadamer and how the principles can be applied to nursing research see Koch (1999).

3.2.2 Phenomenological research

It was not the intention of Husserl, Heidegger and Gadamer to create a research methodology. Their philosophical approaches were built into research designs by later philosophers such as Spiegelberg (1982), Merleau-Ponty (1962), Van Manen (1990), social scientists such as Van Kaam (1966), Colaizzi (1978) and Giorgi (1985) and nurse researchers such as Benner (1984; 1989; 1994), Koch (1993; 1995; 1996), Taylor (1992; 1994; 1995) and Macleod (1996).

Recently, philosophers such as Crotty (1996) have argued that nurse researchers have not been true to phenomenology in their adaptation of the philosophical underpinnings of phenomenology. Crotty (1996) analysed 30 phenomenological nursing research studies published in international academic nursing journals over a three-year period. He argued that nursing research moves away from the philosophy of phenomenology by making generalisations and reducing philosophy to a process. He maintained that nursing phenomenology is a substantial adaptation of main stream phenomenology and, as such, should call itself 'new phenomenology'. He also asserted that the traditional form of phenomenology, which illuminates the 'object versus subject' experience, could serve the purposes of nursing research. However, returning to the traditional form of phenomenology does not lend itself to

the step by step systematic research process that most nurse researchers use as a framework for their studies (Polit and Hungler 1999).

Walters (1995) further argued that many nurse phenomenologists create the misconception that there is a single phenomenological method rather than differentiate between the philosophical approaches of Husserl (1964), Heidegger (1962) and Gadamer (1994).

In order to take on board the criticisms levied at nurse phenomenologists and to move beyond the attempts to apply phenomenology in its literal sense to nursing studies, this researcher decided, for this study, to use an adapted phenomenological method. This was operationalised through in-depth interviewing. The key issues that were included in this adaptation were an exploration of nurses' and patients' lived experience of palliative care. Secondly, interpretation as described by Benner (1994) and Koch (1999) was used to guide the process of data collection and analysis. Thirdly, the process of data collection was characterised by an interactive, participatory relationship between the researcher and the informants. Fourthly, Colaizzi's phenomenological framework was used to guide the process of data analysis. A phenomenological approach, therefore, was used to underpin the entire research process.

3.2.3 Phenomenological data analysis

Many researchers have argued that phenomenology does not lend itself to a step-by-step process of data analysis (Van Manen 1990; Moustakas 1994; Crotty 1996). They asserted that, from a philosopher's perspective, phenomenology is a search for reality and, as such, does not lend itself to study subjects within phenomena. In order to study loneliness, for instance, according to Crotty (1996), you do not have to study lonely people. Crotty argued that the end product of phenomenology is a description of the phenomena, which is presented as a detailed description in the form of narrative prose. This approach does not lend itself easily to nursing research (Polit and Hungler 1999), in that nurses traditionally adopt a more systematic approach to analysing phenomenological data (Omery 1983; Drew 1986; Haase 1987; Beck 1994; Benner 1994). It therefore seems pertinent to explore frameworks for analysing

phenomenological research. The psychologists Van Kaam (1966), Colaizzi (1978) and Giorgi (1985) have developed the three most often used frameworks for analysing phenomenological data in nursing.

Van Kaam

Van Kaam (1966) developed the first clearly-defined methodology for phenomenology. He proposed five stages: preliminary considerations, or considering the specific moment of the experience, identifying the research question evoked by the experience; awareness of explication. Scientific explication is then carried out in which the raw data are listed and then classified. Finally the phenomena are identified and described.

Giorgi

Giorgi's (1985) method also has five steps. The researcher first reads the entire description of the experience to get a sense of the whole. The description is then read more slowly and transition units, or constituents in the experience, are identified. Next, redundancies in the units are eliminated. The researcher then reflects on the constituents and transforms the units into the language of science. Finally, the researcher integrates, and synthesises the insights into a descriptive structure of the meaning of that experience.

Colaizzi

Colaizzi (1978), like the previous frameworks for phenomenological data analysis, used a stage process, but with seven steps, which proceeds as a form of thematic content analysis (Miles and Huberman 1994). The first stage involves reading all of the subjects' descriptions in order to acquire a 'feeling' for them, making sense of the descriptions. The researcher then returns to each transcript and extracts phrases or sentences that directly pertain to the investigated phenomena. This is known as extracting significant statements. The next stage involves 'spelling out' the meaning of these significant statements, or formulating meanings, which are then organised into theme clusters. Referring back to the original transcripts in order to validate them, tests the theme clusters. The findings are then integrated into an exhaustive description of the investigated topic, and an effort made to formulate the exhaustive

description into an unequivocal statement. A final validating stage can be achieved by returning to each subject and, in a single interview question or series of interviews, asking the subject about the findings so far.

The Colaizzi method was used for this study as it most clearly described the process of content analysis. Colaizzi's method is also the most commonly used method in phenomenological nursing research (Drew 1986; Haase 1987; Forrest 1989; Beck 1992; Koch 1995; Baillie 1996). A step by step approach rather than a purely intuitive approach was also thought by this researcher to be useful when the researcher is new to phenomenology. She also felt that a stage process would add to the rigour of the study by making the process of data analysis more transparent.

3.2.4 Nursing research using a phenomenological approach

A CINAHL search (April 2000) for phenomenological studies over an 11 year period revealed 551, 117 of which were based on nursing research. Of the 551 studies, 12 had a palliative care focus and 18 had a cancer focus, and, of these, 12 were nursing related. The palliative care studies relevant to the research questions were explored in the first section of this literature review (Steeves et al 1994; Rasmussen et al 1995; Milne and McWilliam 1996; Larkin 1998).

3.2.5 How a phenomenological approach was used for this study

It is argued that there are a number of key features to a phenomenological approach. The first is that it is a study of lived experience (Van Manen 1990; Wilkes 1991; Ray 1994). In this study patients' and nurses' lived experience of receiving and delivering palliative nursing care was studied, and for this reason this was considered an appropriate methodology to use. Secondly, phenomenology has the potential to illuminate otherwise taken-for-granted assumptions which can exist in the process of giving and receiving care (Seymour and Clark 1998). Phenomenology was, consequently, particularly relevant for this study as it reflects a patient-centred approach and, in so doing, it reflects the participatory ethic of palliative care. The participatory ethic and capability of illuminating taken-for-granted assumptions was achieved for this study by using open-ended questions and focussed in-depth interviews, allowing the patients and nurses to tell their stories. Thirdly, a

phenomenological approach provides an opportunity for studying and making sense of the experience of illness (Oiler 1983; Ray 1985; Anderson 1991; Benner 1994; Robertson-Malt 1999), particularly serious illness (Gullickson 1993; Halldorsdottir and Hamrin 1996; Hopkinson 1999). Making sense of the illness and dying experience was achieved for this study by giving the patients an opportunity to talk about their dying experiences and by exploring nurses' and patients' perceptions of their care.

A fourth feature of the phenomenological method is how the researcher deals with data and with themselves as a researcher (Koch 1994). Consequently, self-reflection guides the research process (Koch 1994). A reflective process was achieved for this study by keeping a reflective diary during data collection. Finally, phenomenology lends itself to participants 'telling their stories' (Benner 1994) as required in this study. Both patients and nurses were encouraged to 'tell the story' of their experience of palliative care in the in-depth interviews. The researcher's role was to interpret or make sense of these stories, creating a different understanding of the situation (Benner 1994). The interpretative process subsequently guided the data analysis in this study.

3.2.6 Summary of phenomenology

Phenomenology was therefore chosen both as a method, as well as the philosophical underpinning for the study. It was determined to be the most appropriate method for allowing the dying patient and palliative nurses to describe their lived experience through the telling of their stories, and was therefore adapted for this purpose.

3.3 Interviewing

Interviewing is the most common method of collecting data in qualitative research (May 1991) and is a versatile and important data gathering technique (Rubin and Rubin 1995). It enables the researcher to share the world of others to find out what is going on, why people do what they do and how they understand their world (Rubin and Rubin 1995). The research interview attempts to understand the world from the informants' point of view, so that the researcher can develop the meaning of peoples'

experiences and reveal their lived world before explaining and reporting it (Kvale 1996).

The research interview may be based on conversations of daily life and is characterised as a professional conversation (Rubin and Rubin 1995; Kvale 1996). By having structure and purpose, it goes beyond the spontaneous exchange of views, as in everyday conversation. A research interview involves careful questioning and listening with the purpose of obtaining valid knowledge (Kvale 1996). The research interview is not normally perceived as a conversation between equal partners, as the researcher defines and controls the situation (Kvale 1996).

There are two main types of qualitative interviews- semi-structured and unstructured. In semi-structured interviews, the interviewer asks questions in the same way each time but the researcher is free to alter their sequence to probe for more information. The interviewer can, therefore, adapt the research instrument to the informant's level of comprehension (Fielding 1994). On the other hand, in unstructured interviews, the researcher has a list of topics to be discussed but is free to phrase the question in any way chosen (Fielding 1994). Unstructured interviews can bring out nuances which might be lost in a more structured approach (Fielding 1994). However, Rose (1994) argued that unstructured interviews are disorganised in that the researcher does not attempt to influence the depth of the interviewees' responses. Nevertheless, however flexible and open-ended the researcher is, any interview will ultimately be structured in some way by both interviewer and interviewee simply because it is a social interaction between two people (Atkinson and Hammersley 1998). Many researchers argue that they fit somewhere along the continuum from semi-structured to unstructured (May 1991; Rose 1994; Rubin and Rubin 1995). Most researchers, therefore, refer to qualitative interviews as focused or in-depth interviews (Field and Morse 1985; May 1991; Wengraf 1992; Fontana and Frey 1994; Marshall and Rossman 1995; Rubin and Rubin 1995). In-depth interviews was the term used for this study.

3.3.1 In-depth Interviews

In-depth interviewing is the most common method of data collection in phenomenological research (Patton 1990; Bergum 1991; Benner 1994; Marshall and Rossman 1995; Sorrell and Redmond 1995; Crotty 1996), and was therefore chosen as the method of data collection for this study. This method is particularly useful when investigating or exploring a new area or when the topic, such as talking about death and dying, is sensitive or complex. In-depth interviews have been described as being more like conversations than a formal procedure with pre-determined response categories (Marshall and Rossman 1995). The researcher explores general topics to help uncover the participants' meaning perspectives, but also respects how participants frame and structure their responses (Marshall and Rossman 1995). It is argued that, in exchange for lower generalisability, the researcher gains greater depth (Rose 1994).

Kvale (1996) argued that, although the techniques of interviews have been extensively dealt with by the literature, the philosophical implications of the mode of understanding in in-depth interviews have seldom been addressed. He maintained that, from a hermeneutical perspective, the interpretation of meaning within the interview is the central theme as opposed to a focus on interrelations, social construction of reality or differences between oral discourse and written text. In a phenomenological approach to an in-depth interview, the concept of conversation and text are pivotal. There is also an emphasis on the researcher's previous knowledge of the subject matter. The phenomenological in-depth interview has a unique potential for obtaining access to, and describing, the lived experience in the everyday world (Kvale (1996).

Kvale (1996) put forward 12 aspects of in-depth interviews that need to be considered when conducting and analysing in-depth interviews. These were all included in the design and process of the in-depth interviews for this study.

life world, referring to the fact that the topic of the interview is the everyday life world of the informant and his or her relation to it;

meaning, in which the interviewer seeks to interpret the meaning of central themes in the life world of the informant (the interviewer registers and interprets the meaning of what is said as well as how it is said);

qualitative, referring to the fact that the interview does not attempt to measure or quantify, but attempts to seek qualitative knowledge expressed in normal language;

descriptive, where the interviewer attempts to obtain open nuanced descriptions of different aspects of the informants lived experience;

specificity, referring to the fact that descriptions of specific situations and action sequence are elicited, rather than general opinions;

deliberate naivete, in other words the interviewer exhibits openness to new and unexpected phenomena, rather than having ready-made categories and schemes of interpretation;

focused, referring to the fact that that the interview is focused on particular themes in the informants lived experience, rather than strictly structured with standardised or completely non-directive questions;

ambiguity, concerning the issue that informants statements can sometimes be ambiguous, reflecting contradictions in the world they live in;

change, concerning the notion that the process of being interviewed may produce new insights and awareness both to interviewer and interviewee;

sensitivity, referring to the issue that different interviewers can produce different statements on the same themes, depending on their sensitivity to and knowledge of the interview topic;

interpersonal situation, concerning the fact that the knowledge obtained is produced through the interpersonal interaction in the interview;

positive experience pertaining to the fact that a well carried out interview can be a rare and enriching experience for the informant, who may obtain new insights into his or her life situation.

3.3.2 Reliability and validity- In-depth interviews

Reliability and validity or testing for rigour can be a particular challenge in qualitative research (Sandelowski 1986; Brink 1991; Miles and Huberman 1994; Twinn 1997; Long and Johnson 2000). Nevertheless, Koch (1994), Koch and Harrington (1998) and Rose, Beeby and Parker (1995) have reflected on the particular issues of rigour in phenomenological research. The main tenets of the

argument relate to the opposing views of interpretative versus transparent approaches to data analysis. The interpretative argument proposes that by making the process of analysis transparent and following a set of rules or framework in order to do this, that this approach moves towards a logical positivist or pseudo-science view of research, that an interpretative, narrative inquiry rejects. In addition, the argument is that qualitative researchers rather than finding novel ways of establishing rigour have instead reapplied quantitative strategies using 'semantic conjuring' (Long and Johnson 2000). Long and Johnson (2000) propose that qualitative researchers focus on alternative means rather than alternative criteria for establishing rigour.

Conversely, the debate asserts that making the process of analysis transparent teaches novices about research, leaves an accurate audit trail for readers of research and diverts some of the criticisms of pseudo-research levied at qualitative research by quantitative researchers.

Although this researcher acknowledges the former argument she perceives that it is necessary, as part of the reflexive process, to enhance the development of interpretative qualitative research and to divert criticisms of bias, to make the process of data analysis as transparent as possible. However, it is acknowledged, that whatever approach is taken, there is a clear imperative for rigour to be pursued in qualitative research. For details of how rigour was established for this study, see section 4.17.

3.3.3 Rationale for using in-depth interviews for this study

In-depth interviews are a popular choice for palliative care research (Plant 1996; Payne 1997) as interviews can be used where writing is difficult or impossible, as when patient are very ill or dying. In-depth interviewing was chosen a method of collecting data, for this study, as it is the most appropriate method for a phenomenological approach. In-depth interviews as a method, therefore, fitted with the overall philosophy and theoretical strategy of the study. In-depth interviews were also chosen as they were the most appropriate method to gather data, in order to allow participants to 'tell their story', a necessary aspect of the phenomenological process, allowing the patients' and nurses' lived experience to be explored.

Moreover, a deep and rich in-sight into informants' experiences would not have been achieved with another method. Another reason for choosing in-depth interviewing is that often people like being interviewed (Payne 1997). This was though, therefore, to make this a more ethically sound method, when researching dying patients. Many people find it therapeutic to be given the opportunity to talk about themselves and have the attention of a researcher (De Raeve 1994; 1996b; Payne 1997). In addition, interviewing allows the meanings of words or phrases to be explored, which observation or the use of questionnaires does not have allowed. In-depth interviews also allow the patients and nurses to be empowered, in other words, they are allowed to tell their story in their own words, rather than be restricted by a standardised measure.

Another reason for using in-depth interviews was that they tend to minimise the distance between the researcher and the researched. A partnership between researcher and participant is an important characteristic of phenomenological research (Bergum 1991; Benner 1994), which was achieved for this study by establishing a rapport with informants early on in the interview (see section 4.16.3). Oakley (1981) argued that there should be a non-hierarchical relationship between researcher and researched and criticised the view of past methodological textbooks where the role of the informant was merely to answer questions. Moreover, in-depth interviews directly mediate between the researched and those who read the final report (May 1996). In-depth interviews, also contain an 'element of adventure a step into the unknown, into the life and feelings of another human being' (Rose (1994). This ties in with the notion of studying the lived experience of informants in phenomenological research, as achieved in this study.

In a study of the lived experience of informants, it is important that the informant leads the process of data collecting. This was achieved for this study by adopting a narrative approach to the interviews, allowing the informant to 'tell their story', by using questions as a topic guide and not impose too much structure on the interview.

Furthermore, when conducting in-depth interviews, the researcher is not completely neutral, distant or emotionally involved (Rubin and Rubin 1995). Researchers form a

relationship with the participant and that relationship is likely to be involving (Wilde 1992; Rubin and Rubin 1995). Indeed, Copp (1996) in her PhD thesis exploring patients' and nurses' experiences of facing impending death, which involved interviewing dying patients, described how she became so emotionally involved that, when analysing the interview transcripts, she saw 'ghosts' of the patients she had interviewed.

A balance between flexibility and consistency in data collection was also achieved for this study. Flexibility in topics and questions is essential for discovering and eliciting the story of the participant. However, consistency is necessary in the types of questions asked, the depth of detail and the amount of exploration versus corroboration covered in an interview in order to draw conclusions (May 1991).

May (1996) argued that interviews in qualitative research can be ambiguous and left open to scepticism regarding their authenticity. He proposed that researchers should develop a more penetrative and critical model for setting out interview schedules. This was achieved for this study by incorporating Kvale's 12 criteria into the process and procedure. The development of an interview schedule also allowed the shortcomings of unstructured interviews to be reduced while allowing flexibility to occur. Key questions were put to all informants, increasing the rigour of the study, but flexibility was maintained by using the schedule as a topic guide and not as a set of rigidly pre-determined criteria. In other words, the use of key questions did not detract from the flow of the interview or impede the informants telling their story. In addition, reflective notes from previous interviews were also used in order to ascertain if any new questions needed to be asked.

For this thesis, this researcher argues that in making the interview process explicit, rather than purely implicit, and subjected to detailed rigour, the disadvantages of using in-depth interviews were minimised.

3.3.4 Summary of in-depth interviewing

In-depth interviewing was chosen as the method for this study, allowing the informants to 'tell their story' in the way they chose. The process (4.16.3) using Kvale's 12 criteria allowed participants to express their feelings and enabled the interview process and procedure to be made more explicit and, therefore, more rigorous and auditable.

After choosing a phenomenological approach the researcher had a concern that something might be missed in terms of exploring perceptions of palliative caring. She, therefore, looked for another technique that might capture the characteristics of caring in a different way. After a lengthy search through the literature and discussion with her supervisors, repertory grids were chosen, as they are specifically about capturing individual perceptions of characteristics. It was, therefore, decided to use a mixed methods approach to the study (see section 3.5 for a justification for the use of two different methods). This raised questions about the legitimacy of using two methods which are answered in section 3.5

3.4 Personal construct theory

Personal construct theory, devised by George Kelly in 1955, is the theory behind repertory grids and is therefore discussed here. It is part of a cognitive idiopathic theory of behaviour which attempts to explain patterns of behaviour in terms of how a person categorises his/her environment (Kelly 1955; Kelly 1963). Kelly's theory is concerned with how people make sense of themselves and the world around them. The essence of the theory is that it stresses the uniqueness of the individual and attempts to understand the person in terms of their experience and perception of the world (Kelly 1963). Therefore, people understand the world they live in by producing a personally organised system of interpretation or constructs of the events they experience. Each interpretation or construct is an abstraction that subsumes some aspect of a repeated event or set of events of which the person is aware. A construct is a person's way of distinguishing similarity from difference- it is not simply a verbal label. Kelly saw constructs as bipolar; that is, one affirms and negates something at the same time. Constructs are not a chaotic jumble but are organised in

a system containing many sub-systems (Beail 1985). Through personal constructs, people are able to predict and control their interpersonal world.

Kelly's theory has been described as a total psychology as it incorporates, within the same theoretical framework, those areas of psychology that are usually separated, namely, learning, cognition, motivation, emotion and psychophysiology (Fransella and Bannister 1971; Fransella 1981). The theory also takes as its subject matter the whole person rather than some fragment of the person's psychological functioning (Winter 1992). The essence of the theory is that it stresses the uniqueness of the individual and attempts to understand the person in terms of their experience and perception of the world. Kelly challenged the psychologists' ability to explain people's behaviour objectively, suggesting that they break with psychological tradition by asking the person outright what they are doing. Furthermore, it is argued that the theory led not only to a psychological theory of personality but also to practical approaches arising out of the resultant understanding of people (Rawlinson 1995).

Kelly's theory is both complex and comprehensive. It is characterised by a fundamental postulate supported by 11 corollaries or assumptions (Table 5). The fundamental postulate is that 'a person's processes are psychologically channelled by the ways in which he anticipates events' (Kelly 1963 p.46).

Table 5 Kelly's (1963) Corollaries and descriptors

COROLLARY	DESCRIPTOR
1. Construction Corollary	A person anticipates events by construing their replications.
2. Individuality Corollary	Persons differ from each other in their construction of events.
3. Organisation Corollary	Each person characteristically evolves, for his convenience in anticipating events, a construction system embracing ordinal relationships between constructs.
4. Dichotomy Corollary	A person's construction system is composed of a finite number of dichotomous constructs.
5. Choice Corollary	A person chooses for himself that alternative in a dichotomised construct through which he anticipates the greater possibility for extension and definition of his system.
6. Range Corollary	A construct is convenient for the anticipation of a finite range of events only
7. Experience Corollary	A person's construction system varies as he successfully construes the replications of events.
8. Modulation Corollary	The variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie.
9. Fragmentation Corollary	A person may successfully employ a variety of construction subsystems which are inferentially incompatible with each other.
10. Commonality Corollary	To the extent a person employs a construction of experience which is similar to that employed by another, his psychological processes are similar to those of the other person.
11. Sociality Corollary	To the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person.

Although there has been little modification of Kelly's basic theory by later personal construct psychologists, his work has been adapted and validated by psychologists such as Landfield (1971), Fransella and Bannister (1977), Beail (1985), Neimeyer and Neimeyer (1990) and Winter (1992). The most widely used application of Kelly's theory is the repertory grid technique (Fransella and Bannister 1977; Winter 1992). Nevertheless, Kelly did, in fact, devise other measures such as the self-characterisation test (Kelly 1955).

Kelly's personal construct theory is not without its critics, notably Yorke (1985) who emphasised the importance of giving a clear indication of the context within which grid data are to be collected. He cautioned against the issue of vagueness related to grids containing elicited elements, arguing that vague elements or elements that have no clear purpose merely provide 'statistical noise'. Yorke (1985) asserted that it is often difficult to specify grid contexts with sufficient precision to eliminate ambiguity of response. Tightening the context may narrow the focus of construing towards particular instances and, therefore, reduces the generalisability of the findings. However, Yorke acknowledged that specification of grid contexts might force the construing of the elements towards particular instances, thereby reducing the generalisability of findings. Others, Fransella and Bannister (1977) and Winter (1992), argued that some researchers have developed grids in isolation from personal construct theory; in other words, without an understanding of the philosophical underpinnings of the technique. The main lesson to learn from this critique is to move away from what Yorke (1985) refers to as 'anything goes as far as grid design is concerned' (Yorke 1985 p.397) and to understand, and adhere to, Kelly's original principles. This researcher, therefore, designed grids with Kelly's original principles in mind, making every effort to produce a rigorous scrutiny of method (section 4.19).

3.4.1 The repertory grid explained

The repertory grid is a structured interview procedure which provides results that are recorded in a matrix procedure. It allows the researcher to obtain a perspective on the informant's world (Winter 1992) by noting what is individual and what is different about the structure and content of an individual's outlook on the world

(Fransella and Bannister 1977). Interviewer bias is reduced and objectivity is maximised.

Any repertory grid must contain a mixture of elements and constructs and a means of scoring them. The size of a grid depends on the subject, time and means of analysis. 'Eliciting elements' is normally the first stage of the grid procedure. Elements are usually people. The most common procedure is to ask the informant to select individuals who best fit certain roles, such as a teacher you liked (Winter 1992). The researcher always supplies *self as I am* and *ideal self* or *self as I want to be* to the elements. There are two important factors to be kept in mind when selecting elements to be used in a grid (Fransella and Bannister (1977): first, the elements must be within the range of convenience of the constructs to be used and second, the elements must also be representative of the pool from which they are drawn.

Once a list of elements is produced, the informant is asked to elicit the constructs. This may be done in triads (Fransella and Bannister 1977; Winter 1992), dyads (Ryle and Lunghi 1970), laddering (Hinkle 1965), constructing pyramids (Landfield 1971) or self-characterisation (Kelly 1963). The most usual method is triads. In a triad approach, the informant is given three of their elements on cards and asked in what important way they are alike and, thereby, different from the third. This is known as the 'minimum context' form of the test (Winter 1992). The informant is then asked to declare the opposite of that construct in order to elicit the opposite, or bipolar, construct. For instance, the pole might be 'depressed' and the contrast 'happy'.

The next stage involves rating or sorting the elements in terms of the constructs which have been elicited. The most common method involves the informant ranking or rating the elements in terms of each construct (Winter 1992). Ranking involves placing all the elements in the order in which the construct applies to them. Where rating is used, this is usually on a three, five or seven point scale to indicate the degree to which the relevant construct applies to each element. An advantage of this method is that it permits the informant the freedom of assigning more than one element to the same point on a construct dimension.

There has been much debate about whether to supply or elicit constructs (Fransella and Bannister 1977; Pope and Keen 1981; Winter 1992). It is considered to be more within the spirit of Kelly's theory to elicit, rather than supply, constructs and elements. However, there are some circumstances where supplied constructs are appropriate (Fransella and Bannister 1977; Winter 1992). One option is to elicit constructs and elements from the population in which the informants belong and then pool a selection of these in a standard grid (Winter and Gournay 1987). In relation to this study, under the guidance of David Winter, it was decided to supply three constructs elicited from the pilot study. All other constructs (n=11) were elicited and all elements (n=12) were elicited except for *self as I am* and *ideal self* which it is usual to supply for grid research (Fransella and Bannister 1977; Winter 1992).

3.4.2 Data analysis of grids

Various methods of analysis can be applied to repertory grids (Winter 1992), the most straightforward and simplistic being an examination of the nature of the constructs and elements (Kelly 1955; Fransella and Bannister 1977). Researchers using repertory grids nowadays are more likely to apply complex statistical procedures with sophisticated software packages (Winter 1992). However, Fransella and Bannister (1977) argued that there is danger in the researcher being caught up in the 'number game' and losing sight of what the person did when they actually completed the grid. They point out that many interesting things can be done by working directly with the grids raw data. For that reason, current guidance on the analysis of grids advises working with the raw data by 'eyeballing' as the first stage of analysis (Winter 1992).

The next stage of analysis usually involves some form of content analysis of the elicited constructs (Winter 1992) using one of the available systems of construct classification. The most commonly used, and reliable and valid, tool is that devised by Landfield (1971). Landfield created his system of content analysis from a study of the exploration of client-therapist congruency in the context of psychotherapeutic relationships. Landfield devised a list of 22 categories (appendix X) which he illustrated with various examples.

The main stage of analysis frequently involves using a statistical package designed for the analysis of grids (Winter 1992). This allows a more precise assessment of the informant's construing (Winter 1992). A repertory grid software package allows a detailed form of quantitative analysis of individual grids. Winter (1992) indicated that the choice of software often depends on what is available to the researcher. He argued that there is a certain amount of similarity between the analyses performed by different packages and few significant differences have been found between the results from different packages (Winter 1992).

For this study, the researcher was advised to use FLEXIGRID, designed by Tschudi (1993) a Professor of Psychology at the University of Oslo. Tschudi (1993) acknowledged the influence of Pope and Keen (1981) and Bannister (1977) when developing his programme. Like most grid software packages, FLEXIGRID is based on principal component analysis of an individual grid (Fransella and Bannister 1977). Principal component analysis is a type of factor analysis that is essentially an analysis of the total variance of the data (Fransella and Bannister (1977).

3.4.3 Reliability and validity of repertory grids

Kelly (1963) indicated that he was more concerned with the consistency of a test than its reliability, and with its usability rather than its validity. Nevertheless, it is necessary to ensure the reliability of repertory grids, as with any data collection tool used for research purposes. The reliability and validity of repertory grids has been discussed in detail by Fransella and Bannister (1977) and Winter (1992), who argue that one of the main failings in terms of lack of reliability and validity in grid use is that they have often been developed in isolation from personal construct theory and without an understanding of the philosophical underpinnings of the technique.

Common methods of assessing the reliability and significance of psychometric tests were designed with nomothetic tests in mind and are, as such, inapplicable to repertory grids, except when grids constructed for general use are considered (Slater 1965). Therefore, particular techniques have been designed to ensure that grids are reliable and valid. Section 4.20 details how these were applied for this study.

3.4.4 Nursing research using the repertory grid technique (RGT)

An extensive search for nursing repertory grid research revealed few studies. Searches for RGT research using PsycLIT for the years 1995-2000 revealed no citations of RGT nursing research. A search using Medline for the years 1966-2000 revealed 107 citations of RGT research, 14 of which were nursing research. A search using CINAHL for the years 1982-2000 revealed 32 citations, 20 of which were nursing RGT studies. The search was also supplemented by cross-referencing articles and conducting a hand search of the key alpha rated journals- Journal of Advanced Nursing, Journal of Clinical Nursing, International Journal of Nursing Studies and Nursing Research. Nevertheless, there has been some interest in RGT research in the past few years by nurses (Pollock 1986; Morrison 1990; Mazhindu 1992; Rawlinson 1995).

The extended search demonstrated a limited number of nursing studies employing the RGT. Moreover, the studies tended to be small (Dyson 1996; White 1996), with low level analysis (Burnard and Morrison 1989). Numbers ranged from 21 nurses (Burnard and Morrison 1989), nine nurses (Dyson 1996), six nurses (White 1996), 48 first year project 2000 pre-registration nursing students and 15 nurses attending a part-time BSc in nursing and nine nurse lecturers (March and McPherson 1996), 60 registered nurses (Retsas and Wilson 1997), 10 registered nurses and 10 elderly residents (Ellis 1999). Standard procedures for the RGT, such as the inclusion of the elements *self as I am* and *ideal self* (Dyson 1996), were ignored. They also demonstrated the use of dyadic rather than triadic methods (Morrison 1989, 1991) and a failure to use an established classification system for content analysis such as that developed by Landfield (1971) to enhance reliability and validity. Other than White (1996), Retsas and Wilson (1997) and Ellis (1999), computer technology has not been employed to analyse grids in nursing research. None of these studies had a palliative care focus.

To provide an example of nursing RGT research, Morrison's study (1989; 1990; 1991) was chosen to be explored in detail here, as the context of the study and the findings most closely resembled those of this study. In a study for his doctoral thesis, Morrison examined the perceptions of trained nurses about the notion of caring. He

interviewed 25 nurses of charge nurse grade using an eight by eight grid. The responses of his sample were categorised into seven areas- 'personal qualities', 'clinical work style', 'interpersonal approach', 'level of motivation', 'concern for others' and 'use of time and attitudes'. He concluded that the ideal caring nurse needs to be kind, genuine, patient, calm, helpful, honest, relaxed, considerate, experienced, flexible, tolerant and understanding, with a pleasant disposition and a sense of humour.

Morrison's study, although revealing, did constrain participants to formulate their responses in terms of the nurse as a carer. It is not clear whether all nurses, if asked in an open way, would have put ability to care as the central most important nursing attribute. He also chose to use a dyadic rather than triadic method for eliciting constructs, despite the fact that it is usual to use a triad method in repertory grid technique. Morrison chose to do this to match each element with the respondent's self. He also supplied elements rather than eliciting them from the respondents. A further limitation of this research is the small sample size drawn from one grade of nursing. In addition, the analysis was restricted to content analysis using the system outlined by Stewart and Stewart (1981). More complex methods, including cluster analysis, factor analysis and principal component analysis, could have been employed. This would have elicited more in-depth findings and provided further validity and reliability to the study. However, other researchers have extended Morrsion's research by supplying his constructs in their studies on caring (Dyson 1996; Ellis 1999). Likewise, the study was important in terms of adding to the discussion on the concept of caring in nursing

3.4.5 Rationale for using repertory grid technique (RGT) for this study

The RGT was considered an appropriate method for this study for the following reasons. Firstly, the individual nature of the procedure allowed informants to use their own words to describe caring, this maintained and respected their autonomy and fitted in with the phenomenological perspective which underpinned the study. Secondly, the conversational and flexible nature of the format, and the fact that there are no right or wrong answers meant that the informants, particularly the patients found this an enjoyable procedure to use. Thirdly, the rigour of the comparing,

contrasting technique ensured that participants elaborated at length their understanding of their perceptions of caring, enhancing the objective nature of the tool. Fourthly, the discipline and structure involved in the procedure ensured that the research questions relating to characteristics of caring were answered, a problem with some unstructured techniques. Fifthly, the grid gives structure to subjective information, which meant that comparison between individuals and between the nurses and patients could be undertaken. Finally, the capacity of the RGT as an interpretative framework and the fact that both qualitative and quantitative data is generated raised the potential of the technique as a catalyst for change. This accentuated its potential as a rigorous and useful research tool.

3.4.6 Summary of RGT

Repertory grids are the data collection tool derived from personal construct theory. Grids are a useful mechanism for eliciting an informant's view of their world from their perspective and are particularly relevant to a study of the lived experience of giving and receiving palliative nursing. A detailed search revealed few nursing RGT studies, none of which had a palliative care focus. This further indicates the importance of exploring the use of repertory grids for a study of nurses' and patients' perceptions of palliative nursing. In addition, the paucity of palliative care research using RGT exemplifies the uniqueness of this study.

3.5 Triangulation (using a mixed method approach)

Triangulation is a term originally used in navigation as a strategy for taking multiple reference points to locate an unknown position. Campbell and Fiske (1959) are acknowledged as being the first researchers to apply triangulation as a research method in their study of the assessment of clinical psychologists. Denzin (1970) defined triangulation as the combination of multiple methods in a study of the same object or event to depict more accurately the phenomenon being investigated.

3.5.1 Methodological triangulation

Most researchers follow the convention of Denzin (1970) who outlined four types of triangulation: data, investigator, theory and methodological triangulation Methodological triangulation is the most commonly used type of triangulation in

nursing research (Redfern and Norman 1994a). Methodological triangulation involves the use of two or more research methods or methods of data collection within a single study (Denzin 1970; Jick 1979; Bryman 1988; Morse 1991a; Bradley 1995). It is most commonly used to describe the combination of qualitative and quantitative methods in a single study (Mitchell 1986; Myers and Haase 1989; Morse 1991a; Knafl and Breitmayer 1991; Cowman 1993; Carr 1994; Redfern and Norman 1994b; Begley 1996). The methods are selected because each explores a different dimension or aspect of the problem being studied. Denzin (1970) further divided methodological triangulation into the 'within method' and 'between method' approaches. The 'within method' approach uses two or more similar data collection approaches in the same study to measure the same variable. The 'between method' approach uses a qualitative measurement approach and a quantitative data collection approach in one study to measure the same concept (Kimchi, Polivka and Stevenson 1991).

The 'within method' approach to methodological triangulation was chosen as the most appropriate method for this study on the grounds that it allowed the exploration of complex ideas within palliative care with many dimensions (Jick 1979).

3.5.2 Rationale for selecting methodological triangulation for this study

The main reason for choosing a triangulation approach for this study was to overcome the intrinsic bias of single method studies (Denzin 1970). Another reason for using this design was to confirm the results and conclusions and provide further rigour and validity to the study (Kimchi et al 1991). The two different, but complementary methods (in-depth interviews and the repertory grid technique), therefore contributed additional pieces to the jigsaw of the study. Using triangulation also allowed a more holistic and contextual portrayal of the problem under study. Another important reason for using a triangulated approach to the research design meant that complementary findings were obtained that strengthened the research results. These complementary findings, added to the rigour of the study by validating each other. Using methodological triangulation also contributed to the theory and knowledge development of the researcher. Morse (1991a) maintained that researchers who subscribe to the philosophical underpinnings of only one research

approach have lost sight of the fact that research methodologies are merely tools to be used to facilitate understanding. 'Smart researchers are versatile and have a balanced and extensive repertoire of methods at their disposal' (Morse 1991a p. 122).

There are however problems associated with mixing naturalistic (qualitative) and rationalistic (quantitative) paradigms. These include the complexity involved in using approaches from opposing philosophical and theoretical viewpoints. Researchers can sometimes increase bias by not using methods to their full potential (Duffy 1987; Morse 1991; Dootson 1995). In addition, some researchers would argue that mixing paradigms weakens the focus of the research question, as research questions should stem from the paradigms in which the question was developed (Polit and Hungler 1999). It could also be argued that the two paradigms are too opposed to be mixed, with one (rationalistic) stemming from the branch of science known as positivism. This is concerned with a search for rules which govern and explain reality and attempts to control events by isolating variables and implementing controls. The naturalistic paradigms shares its assumptions with the historical approach and is concerned with understanding human behaviour. Research drawn from this paradigm is concerned with describing and interpreting situations such as meanings, feelings, attitudes, and beliefs. This difference in epistemological stance may, therefore, cause conflict about the research design (Polit and Hungler 1999)

This researcher moved beyond this debate by choosing a naturalistic paradigm for the study and, therefore, argues that this study is principally qualitative and that phenomenology underpinned her entire research strategy. Methods were therefore mixed paradigms were not mixed. She believes that the use of mixed method approach was a viable option to obtain complementary findings and completeness and therefore strengthen the research findings. Moreover, more qualitative researchers (Smith 1987; Morse 1991; Rose and Webb 1997; Herth 1998; Rose 1999) are arguing that if a combination of philosophical and research traditions help to answer a research question completely then they should be used together. This researcher also addressed the issue of differing theoretical perspectives by choosing to mix methods that were complementary, rather than diametrically opposed. The differing assumptions did not contradict each other, but enhanced each other.

Moreover she felt that adhering too rigidly to only one method would not enhance palliative nursing knowledge (see shortcomings of previous palliative nursing research (Chapter 2), a goal of the study.

The advantages and disadvantages of triangulation are summarised in Table 5.

Table 5 Advantages and disadvantages of methodological triangulation

	ADVANTAGES	DISADVANTAGES
1.	Provides information about informants that would otherwise be overlooked (Duffy 1985). Enhances researchers' efforts to describe and conceptualise the multi-faceted complexity of the human response to illness and health care (Knafl and Breitmayer 1991).	There continues to be a confusion about how the term is used and how authors frame and justify their approach towards triangulation, with a tendency to treat triangulation as an 'inherent good' (Knafl and Breitmayer 1991).
2.	Triangulation also allows for an understanding of the person's world that is not possible in a purely experimental study (Corner 1991).	Cowman (1993) cautions against collecting a volume of data that are subsequently not possible to analyse or which could be treated superficially.
3.	Increases the reliability and validity of a study (Denzin 1970; Corner 1991; Redfern and Norman 1994a; Bradley 1995).	As much of nursing research is inquiry into social issues using naturalistic methods, replication is often impossible (Redfern and Norman 1994a).
4.	Choosing one research methodology narrows the researcher's perspective and deprives them of the benefits of building on the strengths inherent in adopting a variety of research methods. Adhering to one method can also make the researcher ethnocentric, which may distort the slice of reality being investigating (Duffy 1985; Corner 1991; Cohen and Manion 1994).	If not approached cautiously, the result in triangulation may be to enhance the weaknesses of each method and invalidate the whole research project (Morse 1991a).
5.	Triangulation demands creativity in data collection, analysis and interpretation (Redfern and Norman 1994a).	Triangulation is an expensive use of resources (Redfern and Norman 1994a).

3.5.3 Summary of methodological triangulation

Methodological triangulation was employed in this study as a way of enhancing the completeness of the subject being studied, that is, by providing additional and different data. The RGT was used to add to the information collected in the in-depth interviews and to strengthen the methodological rigour of the study. The RGT

generated significant data and provided an invaluable contribution into the researcher's overall insight into the lived experience of the palliative nurse and the dying patient. The use of both in-depth interviews and repertory grids also allowed the researcher to approach the topic of palliative nursing from different angles, enabling deeper insight into the subject being studied to be developed. Moreover, the advantages of exploring characteristics of caring in a deeper way overcame the disadvantages of a purely phenomenological approach. The combination of methodologies thus added rigour to this study in terms of depth and breadth and to the development of the skill base of the researcher, by enhancing creativity in the data collection and analysis.

3.6 Overall summary

An exploration of the literature on the selected methods has indicated that a qualitative design within the framework of methodological triangulation would be an appropriate design for this study. It was deemed the most appropriate design to provide a holistic picture of palliative nursing and to limit the disadvantages of the two methods used. A phenomenological perspective underpinned the study which was operationalised using in-depth interviews and thematic content analysis to explore the lived experience of dying patients and palliative nurses regarding their nursing care.

In-depth interviews were used to explore the lived experience of palliative nursing care from the patients' and nurses' perspectives as well as to explore how the informants perceived the palliative care nurse, in keeping with the phenomenological method. The repertory grid technique was used to discover how nurses and patients characterised good and bad caring and to ascertain whether there were differences between patients and nurses as to what constituted good and bad caring. The use of repertory grids (RGT) allowed measurement to occur, thereby enhancing the rigour of the qualitative data. They also add to the uniqueness of the study as they have not been used before in palliative nursing research.

The congruence between phenomenology and repertory grids and the reasons for using this approach are as follows. Firstly, both the RGT and phenomenological

interviews explore the informants' world from their point of view. Secondly, phenomenology is more closely allied to personal construct theory than grounded theory or ethnography. Thirdly, both phenomenology and personal construct theory recognise the uniqueness of the individual and the importance of understanding the individual in terms of their experience and perception of the world. Fourthly, the in-depth interview combined with the RGT allowed a deeper rapport to develop between the researcher and informants. This fitted with the phenomenological perspective which underpinned the study by allowing the informants' lived experience to be more easily explored. Fifthly, the researcher found the combination of methods enjoyable. The two different techniques allowed an element of interest and variation for both researcher and participants. Sixthly, the two methods appeared to work well together, by validating and enhancing the rigour of the other method. For instance, one of the main findings of the study was that both patients and nurses identified that personal or humane qualities were a feature of a good palliative nurse. The importance of these characteristics and the clear identification of these qualities would not have been possible without the grids. The grids were able to distinguish how highly the patients and nurses rated the characteristics. Finally, the combination of approaches enhanced the study by making it more robust, systematic, and rigorous.

This methodological approach was therefore chosen to explore the research questions for the following reasons. Firstly, phenomenology as a research method involves making sense of illnesses and is therefore useful for exploring the dying experience. Secondly, perceptions of care were usefully explored by using both phenomenological in-depth interviews and the repertory grid technique, both of which examine perceptions from the individuals' perspective. Thirdly, it was decided that examining the nurse and patient in-depth interview data and the repertory grid data separately, and therefore drawing comparisons between the sets of data, was the most appropriate method of discovering the differences between patients' and nurses' perceptions regarding good palliative nursing. Fourthly, using the repertory grid technique enabled the researcher to rate constructs (aspects of caring) against elements (carers), this was therefore deemed to be the most appropriate method for identifying patients' and nurses' characteristics of caring.

In the following chapter the materials and methods are presented.

Chapter 4: Methods

4.0 Introduction

The overall aim of the research was to investigate the role of the nurse in palliative care. The specific aims of the study were (see also 2.8)

1. To explore the concept of the good nurse in palliative care.
2. To discover how nurses perceive good and bad palliative care.
3. To discover how dying patients perceive good and bad palliative care.

4.1 Research questions

1. What is palliative nursing care from the patient's perspective?
2. What is palliative nursing care from the nurse's perspective?
3. Are there differences between patients' and nurses' perceptions as to what constitutes good palliative nursing care?
4. What do dying patients identify as characteristics of caring?
5. What do nurses caring for dying patients identify as characteristics of caring?

4.2 Study design

This was a three-year study using methodological triangulation. Data were collected via in-depth interviews using an adapted phenomenological approach and followed up by repertory grids. A total of 22 registered nurses and 22 dying patients participated in one in-depth interview. The same sample (22 nurses), but only nine of the original sample of patients, then completed a repertory grid. The in-depth interviews were analysed using thematic content analysis. The repertory grids were analysed using content analysis and principal component analysis, using a software package called FLEXIGRID. Descriptive and inferential statistics were applied to the repertory grids.

The study took place between 1994-1997. Initially, the study was conducted in East Anglia where the pilot study data were collected. Due to personal circumstances, the author moved to Scotland. The data from the main study were, therefore, collected in Scotland.

4.3 Study sites

The study sites were two acute hospitals and two specialist palliative care units (hospices). For the purposes of this study, the term 'hospice' is used to describe specialist palliative care units although it is recognised that the latter term is now more accepted terminology (NCHSPCS 1995).

The study sites were chosen for the following reasons. Firstly, the researcher wanted to achieve a complete picture of palliative nursing and living with a terminal illness. Hospices are specialised palliative care areas, where the goal and focus of care are palliative. In addition, the health professionals working in them usually share common goals and are mostly qualified in palliative care. On the other hand, in hospital settings the focus of care is usually acute and curative. Health care professionals in hospitals may specialise in a variety of areas but not usually palliative care. Despite these differences, most patients with life-threatening illnesses, including cancer, tend to die in hospital settings. The researcher felt that to encompass these differences, both settings needed to be included. It was not her intention, however, to *measure* the differences between palliative care in hospital and hospice settings.

Secondly, the researcher wanted to avoid the bias which can be levied at studies where a single setting is used. Thirdly, hospices may attract palliative nurses who have different perceptions, attitudes and education regarding palliative care, to hospital nurses. In order to limit the bias that may occur if only nurses with common attitudes and perceptions were included in the study, different settings (two hospitals and two hospices) were included.

Fourthly, in the researcher's experience dying patients may have different experiences in hospices from hospitals. Hospices are usually smaller, independent of the NHS-and therefore more remote from the trials and tribulations that go with the modern day NHS- and have a higher staff to patient ratio. Finally, in the researcher's experience patients often praise hospice care. She, therefore, felt that bias would be reduced and a more complete picture of palliative nursing would be obtained if hospital and hospice settings and more than one hospital and hospice setting were

included. The study sites also included urban and rural areas, to provide additional variability.

4.3.1 Profile of study sites

Hospice A

Hospice A is an independent hospice situated in a rural setting in Scotland and covers two health board areas. It has 18 beds, a day care department which opens Monday-Friday, taking about 80 patients per week, and a home care service with approximately 100 patients on its books at any one time. The hospice is staffed by a multi-disciplinary team including registered nurses, nursing auxiliaries, home care sisters (Macmillan nurses), medical consultants, a director of nursing services, a hospice director, an administrator, a physiotherapist, an occupational therapist, a social worker, a chaplain and volunteers. The hospice is funded partly by contracts with two health boards (50%) and partly by voluntary contributions (50%), which are mainly received from the local area.

Hospice C

Hospice C is an independent hospice situated in an inner-city location in Scotland and covers part of one health board area. It has 14 beds, a small day care department, which opens Monday-Friday and a home care service that has approximately 80 patients on its books at any one time. The hospice is staffed by a multi-disciplinary team including registered nurses, nursing auxiliaries, home care sisters (Macmillan nurses), a medical consultant, a director of nursing services, a hospice director, an administrator, a social worker and volunteers. The hospice is funded partly by a contract with one-health board (45%) and partly by voluntary contributions (55%) that are mainly received from the local area.

Hospital B

Hospital B is a district general hospital NHS Trust situated in a medium-sized rural town in Scotland. It has 480 beds, including 26 wards, a maternity department and an intensive care unit. The hospital has a clinical nurse specialist in cancer care whose role includes delivering cytotoxic chemotherapy treatment to outpatients.

Hospital D

Hospital D is a district general hospital NHS Trust situated in a medium-sized industrial town in Scotland. It has 520 beds including a maternity department and an intensive care unit. The hospital has a clinical nurse specialist in cancer/palliative care whose role includes delivering cytotoxic chemotherapy treatment to outpatients.

4.4 Population

There were two populations for this study - nurses and patients. The population of nurses were registered nurses delivering palliative care to dying patients and their families. Qualified nurses only were chosen for the following reasons. The study aimed to explore the lived experience of the *expert* palliative care nurse. This researcher endorses the view that expertise in nursing is achieved through a combination of several factors. This includes a specific knowledge base which is acquired through professional and academic knowledge and clinical experience in a particular area. In addition, it is acknowledged in both the literature and practice that expertise in nursing cannot be achieved without, at the very least, a basic qualification in nursing, and usually an academic qualification in a particular clinical speciality (see Literature review section 2.3.1).

The population of patients was those who had received a palliative care diagnosis; in other words, patients suffering from a life-threatening illness such as cancer, progressive neurological disease, or chronic respiratory disease, from which they were unlikely to be cured. The researcher chose to include patients with non-malignant disease for the following reasons. She felt that as cancer makes up only a small portion of the number of patients dying in the U.K. from life-threatening illnesses, a complete picture of palliative nursing would not be achieved if only cancer patients were included. In addition, most hospices in the U.K., (including the two hospices used as study sites) now include patients with other life-threatening illnesses, such as progressive neurological disease. Finally, specialist palliative care has recently been criticised (Addington-Hall 1998) for neglecting patients dying from other illnesses, when they may benefit from a palliative care focus. The current argument, which this researcher endorses, is that palliative care should be available to all on the basis of need rather than diagnosis.

4.5 Samples

A non-probability, purposive sample was used for this study. In keeping with the phenomenological aim of illuminating the richness of individual experience, the sample size was deliberately small. Table 7 depicts the sample distribution. The sample size of 22 nurses and 22 patients was chosen for the following reasons: to reflect an appropriate sample (five to six informants) from each site; to enable a sample to be drawn from general hospitals as well as specialist palliative care settings (see section 4.3), and in addition, to draw a sample from general and specialist palliative care settings. The sample size was also chosen to provide sufficient numbers for the repertory grids. Moreover, a smaller sample size would have reduced the opportunity to compare findings in relation to the repertory grids. Furthermore, as a degree of sample attrition, particularly given the patients' state of health, was expected (see section 4.16.1) and as two methods of data collection were being used, it was considered appropriate to have an adequate sample size at the beginning, in case attrition occurred.

Table 7 Sample distribution

HOSPICE A		***HOSPICE C***	
No. of Nurses	**No. of Patients**	**No. of Nurses**	**No. of Patients**
7	7	4	4
HOSPITAL B		***HOSPITAL D***	
6	*6*	*5*	*5*

4.5.1 Patients: (n=22) inclusion criteria

The patient sample was people with a diagnosis of a life-threatening illness who were being cared for in either of the acute hospitals or hospices used in the study, and who met the following inclusion criteria:

- diagnosis of a life-threatening illness such as cancer, motor neurone disease, multiple sclerosis, or chronic heart disease, or chronic respiratory disease;
- life expectancy of no more than two years but not less than two weeks;
- awareness of their diagnosis;
- ability to communicate in English verbally.

4.5.2 Nurses (n=22) inclusion criteria

In order to be included in this study, the nurses had to meet the following criteria:

- must be a registered nurse;
- have post-registration experience of at least two years;
- possess a post-registration qualification in palliative care;
- be employed in one of the participating study sites.

4.6 Access procedure for pilot and main study samples

Access was sought and granted from each of the four research sites prior to seeking ethics approval for the study. Directors of Nursing (DNSs) at all four sites were approached regarding the study and permission was gained to access both nurses and patients (Appendix I). Access to both samples was sought from the DNSs as the method demanded that it would be the nurse who would identify a suitable patient. Each DNS stated independently that contact would be made with the Medical Director for consultant access as it was felt that because this was a nursing study, this was the most appropriate way of securing access. Two of the Medical Directors subsequently wrote to the researcher expressing their interest in, and commitment to, the study.

After Ethics Approval (Appendix II) had been granted, the researcher approached the ward manager of each study ward. The ward manager then suggested nurses who fulfilled the study criteria to the researcher. The potential bias here was taken into account and noted as a study limitation. The bias was not, however, systematic as four study sites were used and, therefore, more than four different ward managers were approached.

The nurses were then approached individually and were asked if they wished to participate in the study. Each potential nurse informant was given a written information sheet (Appendix III) concerning the study, in order to fulfil the ethical issue of informed consent. . If the nurse agreed, an appointment was made for the first interview. At the end of the interview, each nurse was asked to identify a patient who met the study criteria as explained by the researcher. In the main, nurses

required several weeks, and several prompts, to identify a suitable patient (section 4.8.4).

Access to patients was gained via the nurse, as stated above. Providing that the patient agreed, the nurse then introduced the researcher to the patient. The researcher explained the study to the patient and gave them a written information sheet (Appendix IV). If the patient agreed to participate, an appointment was made to conduct the first interview.

This pattern of recruitment was chosen as it fits with both the research questions and the methodology. Therefore, approaching nurses who fulfilled the study criteria and asking them to choose suitable patients, was appropriate for a method (phenomenology) that is interpretative and narrative, with an aim of illuminating the informants' lived experience, where the aim is to create an interactive involvement, a partnership between researcher and informant.

The pattern of recruitment was also suitable for the research questions, which set out to explore what palliative nursing was from both the palliative nurses, and the dying patients' perspectives. As this was inherently a nursing study, about nurses and with nurses, it was deemed more appropriate to approach nurses for access than doctors.

The author does acknowledge, however, that as with other interpretative studies and studies using informants with sensitive issues such as dying, that other patterns of recruitment could have been used. A recruitment pattern that allowed any patient who fulfilled the study criteria to voluntarily participate (see gate keeping section 4.8.2) may have been appropriate. However, this form of recruitment raises ethical issues which may not have been endorsed by the relevant ethics committee

4.7 Ethics approval

The researcher gained ethics approval for the pilot study in East Anglia and the main study in Scotland; therefore, three different Ethics Committees were approached (Appendix II). Duplication of paperwork and repeated answering of similar questions was time-consuming but unavoidable, due to the researcher's move to Scotland.

4.8 Ethical issues

As the dying experience was the subject of the study, it was thought that many ethical issues would arise, given the sensitivity of the topic. Issues included the researcher's role with research informants, tape-recording in-depth interviews, confidentiality, the giving of informed consent and gate keeping. The four main principles of ethics- beneficence, nonmaleficence, justice and autonomy- were considered in relation to these issues (Beauchamp and Childress 1994).

4.8.1 Beneficence and nonmaleficence

The principles of beneficence and nonmaleficence refer to doing good and not inflicting harm. They were applied to this study in relation to the issues of informed consent and conduct of the interviews. Informed consent was addressed by giving all informants written and verbal information about the study (Appendix III, Appendix IV) prior to their involvement in the study. All informants were then asked to sign a consent form (Appendix V) at the start of the first interview. Their consent was sought again at the beginning of the second interview- the repertory grid.

There are particular issues to consider in relation to providing informed consent for dying patients; indeed, these arguments can be used to support the reasons for interviewing dying patients for research purposes. For instance, there is the issue of why dying people choose to consent to participate in research involving in-depth interviews. They may consent to participate in research projects for several reasons: it may be one way of adding meaning to their illness (Twycross and Dunn 1994; Aranda 1995); patients may also attach importance to being able to help someone else at a time when their usefulness in society is being challenged. Patients may also see the interview as some form of closure at the end of their lives. The very nature of a one-one interview may be therapeutic in that a researcher may offer time, a non-judgmental listening ear, interest and close attention. De Raeve (1994; 1996a; 1996b), a moral philosopher with a nursing background, has argued extensively that research with dying patients can be seductive and, because some research informants may greatly value the experience, this, in itself, does not necessarily justify the approach or the method.

The possibility of raising powerful, emotional and even painful responses in the dying and bereaved person was, therefore, considered carefully. However, many of the patients who participated in the study stated overtly how helpful they had found talking about their illness, thereby justifying, perhaps for themselves, the purpose of participating in this research.

Role confusion is another issue as far as minimising harm to patients involved in research is concerned. In other words, the informant confuses the role of the researcher with their role as a health professional. The conflicting issue here is therefore, to whom is the informant giving their consent? - The researcher or the doctor or nurse caring for them? This is a particularly important issue when the informant knows the researcher. None of the patients, but over half of the nurses, knew the researcher. The researcher, therefore, explained to informants that participation in the study was voluntary and that the study was separate from the researcher's work as a hospice lecturer.

Likewise, the researcher considered her own vulnerability, particularly when dealing with emotive issues. The researcher, therefore, used reflective practice, which included keeping a field journal for the duration of the study. She also identified someone who could be consulted for support for the period of the study. This individual provided a sounding board to discuss difficult or distressing issues.

4.8.2 Autonomy

Personal autonomy refers to personal rule of the self, while remaining free from controlling influences that prevent meaningful choice (Beauchamp and Childress 1994). Both the nurses' and patients' autonomy was respected in relation to providing the conditions for informed consent, preserving confidentiality, giving informants the control to stop the interview or repertory grid at any time and considering the researcher's role with research informants. All informants were informed that they could withdraw from the study at any stage if they so wished and, if they were patients, that this would not affect their care in any way.

Autonomy was also respected in the fact that informants chose to participate in the study; they were not coerced in any way. Furthermore, by recounting the parts of

their story that they wished to tell the researcher, informants retained ownership of their information.

The anonymity of informants and the participating institutions or organisations in the interview transcripts and presentation of findings was preserved through the allocation of a pseudonym, chosen by the informants themselves in the majority of cases. All names were eradicated from the transcripts and all hospitals and hospices were referred to as hospital B or D or hospice A or C.

The issue of whether to tape-record the interviews was considered in relation to the issues of confidentiality, anonymity and intrusion. All informants were asked whether they minded that their interview was tape-recorded, and none refused. All tapes were kept safe and secure in keeping with the Data Protection Act (1998) and destroyed at the end of the study. The incidence of intrusion was minimised by using a micro-cassette recorder. The above issues were included in the ethics committee applications and approved by the relevant Local Research Ethics Committees.

4.8.3 Justice

The principle of justice refers to fairness and desert. In other words, one acts justly towards a person when that person has been given what they deserve (Beauchamp and Childress 1994). Both nurses and patients who met the study criteria were invited to participate in the research. The study also applied the principle of justice by validating informants' participation throughout the study. In addition, informants were given an opportunity to withdraw from the study at any time if they so wished. Only one patient with chronic heart disease chose to withdraw at the end of the first interview, refusing to participate in the repertory grid because she felt too ill to complete another interview.

Another important ethical issue raised in this study was 'gate-keeping' by the nurses when asked to recruit patients. The issue of 'gate-keeping' relates to the ethical principles of beneficence and nonmaleficence as well as patient autonomy versus paternalism of health professionals. However, it is particularly pertinent in terms of justice and so is referred to in this section.

The researcher did not anticipate the issue of 'gate-keeping' before the study commenced. It involved many of the nurses in the study requiring several prompts to recruit suitable patients. However, the issue appeared to be that that the nurses did not want to suggest patients for inclusion in the research, and not that there were unsuitable patients in their care. The nurses may have felt that they were protecting the patients by not approaching them about the study. Over-protection has been alluded to in other studies regarding dying patients (Raudonis 1992; Aranda 1995). Raudonis argued that in protecting patients' human rights regarding participation in research, patients might be prevented from exercising their right to self-determination. Over-protection in this study may, therefore, have affected the patient's right to personal autonomy, particularly as once patients were chosen and approached by the researcher, none refused to participate and many stated how much they had enjoyed participating in the study.

Voluntary participation, in other words circumventing the nurse's role in recruiting patients, by advertising directly to patients, in the form of letters or posters in in-patient or outpatient settings, may have been more fair. All patients who fulfilled the study criteria would thus have been given the opportunity to participate in the study. This would however, have proved problematic in terms of patient selection in other ways. For instance, it would have been difficult to recruit the appropriate sample size as some areas may have received more volunteers than others. Moreover, permission from the appropriate health care professionals responsible for the patient would still have needed to be sought, in accordance with ethics committee criteria. This would have returned the researcher to similar problems in terms of gate-keeping as health professionals could still have refused their permission for patients to participate in the study.

4.9 The process of gaining informed consent

Both written and verbal informed consent were obtained from all informants. When approached to participate in the study, both nurses and patients were given a written information sheet (Appendix III and Appendix IV). The study was also explained to them by the researcher and then informants were invited to participate. At the first interview (in-depth interview), the study was explained to informants again. Consent was sought verbally and informants asked to sign a written consent form (Appendix

V). In the case of patients, a witness was also sought to the patient's signature. Consent was re-sought at the beginning of the second interview (repertory grid), in order to ensure that patients still wanted to continue in the study and that they understood what participating entailed. Informants were reminded that they could withdraw their consent and participation in the study at any time.

4.10 Interviewer training

The researcher undertook a period of in-depth interview training before the commencement of the pilot study, consisting of a 10-week course, which was part of an MA in research methods. Instruction on interview technique was obtained, as well as how to develop an interview schedule and how to carry out interview analysis. After the period of instruction, the researcher developed topic areas to be covered in the interviews.

4.11 Data collection tools: in-depth interviews

4.11.1 Design of prompt schedule

The prompt schedule (Appendix VI, Appendix VII) was constructed on the basis of the literature reviewed and researcher experience, and developed from the research questions. The key areas developed were positive and negative experiences of palliative nursing care and the characteristics of an expert nurse in palliative care. As patients were going to be asked to 'tell the story' of their illness, it was decided to have an identical, initial prompt which was open-ended and invited them to talk to the researcher.

The same prompt schedule, apart from the opening question, was used with the nurse sample. Specifically, they were asked to describe their understanding of effective palliative care and to say how well they felt they met their own criteria for an expert nurse in palliative care (Appendix VI).

A prompt schedule was used for the following reasons. Firstly, as a way of adding rigour to the interview process, by making it more transparent and therefore auditable (see section 4.17). Secondly, to aid analysis. By covering key topics related to the research questions, the first stage of data analysis was made easier. Finally, to ensure

that the same topics were covered in interviews, this, therefore, improved consistency.

In the following sections, the key areas from the prompt schedule are described.

4.11.2 Telling the story

Recent literature has highlighted the therapeutic benefit of allowing patients to 'tell their story' (Heiney 1995; Abma 1998; Banks Wallace 1998). Storytelling is particularly useful for people experiencing a life crisis or major life transition (Heiney 1995). It allows them to give their life purpose and meaning as well as obtaining personal integration, and may bring about a sense of mastery and self-enhancement.

Storytelling was therefore used as an approach in this study in order to allow communication to be developed, trust built, and to enable the researcher and informant to work towards a common purpose. 'Storytelling' also lends itself to a phenomenological approach to data collection, where the focus in interviews is on developing a rapport with the researcher, to allow the informant's experience to be explored.

4.11.3 Positive and negative experiences of palliative care

It has been stated that there are many problems involved with asking patients about their views of their nursing care (Bond and Thomas 1992; Thomas and Bond 1996). These problems tend to be related to a lack of conceptual rigour and methodological investment. Using qualitative measures and being clear regarding the purpose of the study can, in some way, obviate these problems.

The use of an interview style that allowed informants to describe positive and negative experiences was chosen for the following reasons. It was felt that one of the advantages of focussing on incidents was that, in addition to facilitating recall, informants could identify and clarify feelings and meanings which they may attach to these incidents but otherwise be unable to articulate. In addition, the researcher felt that a more complete picture of palliative nursing would be obtained if both positive and negative experiences were included. The researcher felt that informants,

particularly patients, were more likely to recall negative incidents if they had just been asked to recall a positive experience.

Both nurses and patients were, therefore, asked to describe positive and negative incidents. The patients were asked to describe incidents where they felt their care had been either particularly good or particularly bad. The nurses were asked to describe incidents where they had provided, or been involved with providing, particularly good or particularly bad care (Appendix VI).

4.11.4 Good nurses in palliative care

It was decided to explore the nature of expertise in nursing practice (see Chapter Two section 2.3.1) for the following reasons. Firstly, it was felt that explaining what an expert is, and identifying the skills of an expert, or good nurse, could provide a framework for practice which may be used as a guideline for teaching palliative nursing. Moreover, elucidating and interpreting the role of the expert nurse could allow a deeper understanding of the nature of everyday nursing practice and the complex nature of nursing. In addition, if expert palliative nursing practice was explained, it could provide a model for palliative nurses to work towards, as well as a framework for career progression. Finally, the researcher felt that it would be easier for informants to describe a good nurse in palliative care, rather than talk about palliative nurses generally.

Key questions were therefore asked to both nurse and patient informants in order to ascertain how they perceived expert palliative care nurses (Appendix VI, Appendix VII).

As described in section 4.14, it was decided, after the pilot study, not to use the term 'expert' for this study in order to avoid confusion. Instead, the patients and nurses were asked to describe a 'good nurse' in palliative care as a way of facilitating the interpretation of the lived experience of a palliative care nurse (Appendix VI, Appendix VII).

4.11.5 Effective palliative care

It was decided to ask informants to describe what they thought effective palliative care meant for the following reasons. Firstly, it was decided to seek clarification from informants as the term has been regarded with some ambiguity. Likewise, by asking informants for their definition of palliative care, any direction on the part of the researcher was avoided. It also allowed nurses from all settings to recount their perceptions of effective palliative care.

4.12 Data collection tools: repertory grid

4.12.1 Design of repertory grid

The repertory grid was constructed on the basis of the literature reviewed and expert advice and training on repertory grids. Furthermore, as the repertory grid was new to the researcher at the outset of the study, a period of becoming familiar with this method was necessary. The researcher had several meetings with David Winter, an acknowledged repertory grid expert, both before data collection commenced and throughout the course of data collection and data analysis. The purpose of this advice was to ensure that the process was rigorous and to discuss any important issues arising from the data. The researcher also sat in on a repertory grid for a study on agoraphobia in order to observe the procedure.

The key aspects of the design and construction of the repertory grid are outlined in the next section.

4.12.2 Elements and constructs

After reviewing the literature and receiving advice and training, the researcher decided to use the procedure described by Beail (1985) and Winter (1992). This is the most common method, and the easiest to use. The procedure involves three stages: eliciting elements, eliciting constructs, and completing the grid (section 3.4.1). The same format was used with both the nurse and patient samples.

Another consideration after choosing the procedure was to decide on the size of the grid. It was decided, in consultation with David Winter and the researcher's supervisors and after using a 12x11 grid in the pilot study (section 4.14), to devise a 12x14 grid. There are no rules about the number of elements and constructs which

should be contained in a repertory grid, although Winter (1992) indicated that grids with more than 20 constructs are unlikely to be useful.

Elements

It was decided that, as the focus of the repertory grids was to ascertain aspects of caring, the 12 elements for this study would all be carers. In order to elucidate a clearer picture of the informants' views of caring, it was decided that the carers would be health professionals including nurses, family members and friends of the informants. To elicit both positive and negative aspects of caring, the ten elements were made up of five people the informants would like looking after them and five people they would not like looking after them. Furthermore, in order to build a comprehensive view of how the informants viewed health professionals, family and friends as carers, it was decided to ask each informant to have at least one person from each of the three groups in their five elements. As is usual with repertory grid studies, the elements '*self*' and *'ideal self'* were supplied, allowing the researcher to explore how the informants viewed themselves and their ideal selves as carers.

A further consideration, as far as the design of the grids was concerned, involved considering how to present the elements. The usual form of presenting elements is to have them written on cards. The researcher, therefore, arrived at each repertory grid interview with a set of 12 blank cards.

Constructs

The constructs for this study were mainly elicited. The three supplied constructs were derived from the pilot study (section 4.14). Constructs were elicited using triads (see section 3.4.1).

4.12.3 Grid form

A blank grid form (Appendix VIII) was devised in which to input the data. This was based on the standard form developed by Kelly (1955). The researcher used a grid form to input data during the interview procedure. The grid form was, therefore, designed to fit on one page of A4.

4.13 Interview location

Both the in-depth interviews and repertory grid interviews for the pilot study and main study were held either in the hospital ward, the hospice ward or the hospice day-care of the study sites. Patients' homes were also used as interview locations in the main study if that was their wish. The room used was usually a quiet area, free from distractions. The location of interview site was the choice of informants, and was therefore based on a practical rather than academic or theoretical decision. The researcher is of the view that the location of the interview did not, in itself, affect the quality of the data generated.

4.14 Pilot study

A pilot study is a small-scale version, or trial run, of the major study. The function of the pilot study is to obtain information for improving the project or assessing its feasibility (Polit and Hungler 1999).

4.14.1 Aims of the pilot study

The aims of the pilot study were:

- to test the in-depth interview schedule format;
- to test the in-depth interviewing technique;
- to test the repertory grid format;
- to test the in-depth interview thematic content analysis methods;
- to test the use of the repertory grid analysis package FLEXIGRID;
- to test the quality of the data generated;
- to test the feasibility of the study.

4.14.2 Pilot sample

A non-probability, purposive sample, was used for the pilot study. The informants were selected according to the inclusion criteria as set out in section 4.5.1 and 4.5.2. The sample size for the pilot study was seven nurses and three patients, approximately 25% of the main study sample. None of the pilot study sample was included in the main study. The sample size was unable to be matched exactly, due to constraints on time for the pilot study. With hindsight, the researcher could have employed fewer nurses to recruit an equal number of five nurses and five patients.

However, in light of the main study, it is not believed that this created any particular difficulties.

4.14.3 Conduct of pilot study

The pilot study was conducted in one hospital and one hospice in East Anglia from January 1994 - May 1994. Access was gained as in the procedure outlined in section 4.6. Ethics approval was granted from the Cambridgeshire Local Research Ethics Committee in January 1994 (Appendix II). Verbal and written informed consent were obtained from all informants, and confidentiality and anonymity were protected at all times in line with the principles as outlined in section 4.8.

The tools tested in the pilot study included the in-depth interview schedule and the repertory grid. The in-depth interview prompt guide had been developed as detailed in section 4.11. The repertory grid was developed as detailed in section 4.12. The in-depth interviews were undertaken first with a nurse, reasons for this are outlined in section 4.16.1. Approximately seven days later, the repertory grid was then carried out with the same nurse. The nurse was then asked to select a patient whom they had cared for and who fulfilled the study criteria as outlined to them by the researcher. An in-depth interview was then undertaken with the patient, followed by a repertory grid after at least a seven day gap. This procedure was carried out until the pilot sample size was fulfilled. The in-depth interviews were analysed using thematic content analysis according to the procedure outlined in section 4.18. The repertory grids were analysed using the software package FLEXIGRID, but were not subjected to statistical analysis to compare grids.

4.14.4 Findings from the pilot study

Although the majority of questions asked in the interviews were answered as expected, some alterations were made in relation to how the interviews with patients commenced. The first question asked if the patient could describe what s(he) thought palliative care meant. As none of the patients could answer this question, it was decided to begin with a more open question such as "can you take me back to the beginning of your illness and tell me what happened?". This allowed the patient to tell their story, as well as putting them at ease, and was in keeping with the narrative nature of phenomenological inquiry. This approach seemed to increase the flow of

the interview, allowing rapport to develop more easily between the researcher and informants.

Another question with which some of the nurses and patients had difficulty related to the use of the term 'expert nurse'. Some of the nurses asked the researcher whether 'expert' was as described in Benner's (1984) study, and one patient needed the question re-phrased. In light of the need to clarify the term 'expert nurse' and on further reading of the literature, it was decided to re-phrase this question for the main study using instead the term a 'good nurse' in palliative care.

The second aim was to test the in-depth interviewing technique. Both nurse and patient interviews flowed well. All patients talked freely about their experiences, particularly their feelings about their impending death, and all informants provided examples of negative and positive care experiences.

The use of a micro-cassette recorder to record the in-depth interviews proved useful and all informants appeared to ignore the recorder. For the main study, the researcher decided to take extra tapes and batteries to guard against the recorder failing and purchased a detachable microphone for the cassette recorder to enhance the clarity of recording. Although the use of a micro-cassette recorder does not produce as clear a recording as a normal tape-recorder, it facilitated transcription and served its purpose of being unobtrusive. As transcribing the interviews took up a major amount of the interviewer's time (up to 10 hours for one interview), it was decided to employ someone to transcribe the interviews for the main study.

The third aim was to test the repertory grid format. Although the repertory grids lasted 45-65 minutes, this did not seem to be a problem for patients or nurses. Two of the three patients stated how much they had enjoyed completing the repertory grid. Minor changes and adjustments necessary for the main study were a hard surface, such as a table, for sorting cards, remembering to present three different elements in triads, and sorting the cards for rating purposes. In addition, one patient informant did not realise that the researcher was referring to health care professionals when the term 'professional' was used. Consequently in the main study 'health care professional, such as nurse or doctor' was employed.

The fourth aim was to test the in-depth interview thematic content analysis. The thematic content analysis was time-consuming, as expected. The researcher used aids such as 'search' and 'cut and paste' on the word processor for the main study. She also decided to set aside a period of two months unpaid leave to complete both in-depth interview and repertory grid analysis for the main study. This allowed the researcher to become immersed in the data and facilitated the interpretation needed for phenomenological analysis.

The fifth aim was to test the use of the repertory grid software package FLEXIGRID. Access to the computers based in David Winter's department enhanced the use of FLEXIGRID (Tschudi 1993). This meant that if the researcher encountered a problem there was always a knowledgeable helper at hand. A drawback encountered in the pilot study was that no measures were used to compare the grids. Statistical advice was, therefore, sought for this purpose for the main study.

The sixth aim was to test the quality of data generated by the pilot study. The quality of data analysed from the interviews seemed good, and gave the researcher an opportunity to reflect on the data and how it related to the literature. The researcher took the opportunity to attempt to write up the findings as a report for her transfer from MPhil to PhD.

'Eyeballing' the repertory grids revealed that most respondents (n=8) had used the word 'caring' in their constructs. The words 'trust' and 'someone to talk to' were also used by nearly all respondents. After seeking advice from an expert in repertory grids and from her supervisors, it was decided to supply three additional constructs for the main study. These were 'caring - not caring', 'someone I can talk to - someone I can't talk to', and 'someone I trust- someone I don't trust'.

Landfield's (1971) classification system for construct classification (chapter 3 section 3.4.2) proved a useful tool for classifying the content analysis of the repertory grids. Categorising the constructs under particular headings allowed the researcher to see commonalties in the use of constructs by both nurses and patients and was, therefore, also used for the main study.

4.14.5 Summary of the pilot study

The changes required by the pilot study were not substantial enough to require re-piloting. Although there were similarities between the in-depth interviews and the repertory grid data, distinct differences were noted, demonstrating that the combination of these two methods seemed to provide richer data and a more holistic portrayal of the experience. The pilot study was feasible and demonstrated the need for the work to proceed to a main study.

4.15 Main study

As with the pilot study, the main study consisted of a combination of two methods of data collection- the in-depth interview and the repertory grid. The process of each interview is described below. As noted in section 4.2, the study was relocated to Scotland due to personal circumstances which necessitated a re-negotiation of access and ethics approval. The main study took place from August 1995-December 1996. Data analysis was completed in August 1997.

4.16 Data collection: in-depth interviews

The following section outlines both the procedure and the process of the in-depth interviews.

4.16.1 The interview procedure

The in-depth interviews were conducted before the repertory grids. At the in-depth interview for both patients and nurses, the researcher repeated the purpose of the study. All informants were asked to sign a written consent form (Appendix V) and, in the case of patients, a witness to the informed consent also signed (either a nurse or relative). It was explained that participation in the study was voluntary and informants were free to withdraw their consent at any time.

Both patients and nurses were seen alone by the researcher for data collection. This is particularly significant as far as the patients were concerned. It was decided to interview patients alone, that is not with a relative, friend or health professional present for the following reasons. Firstly, by being interviewed alone patients were able to talk freely. If they had had another person present, they may have withheld

information that they did not want the other person present to hear. Secondly, there is evidence that carers' and dying patients' views of their care can be different (see literature review section 2.2.2). By interviewing patients alone these discrepancies in perceptions were avoided.

Interviewing patients by themselves did not pose any problems for this research, as no patient requested that a family member or other person be present at their interview, indeed, without prompting, several patients, when interviewed in their own home, asked their family member to leave the room

Assurances concerning confidentiality and anonymity were given to each informant in accordance with requirements from the Ethics Committees. Patients seemed to anticipate that their conversations would be handled confidentially and that their anonymity would be protected. Great care was taken to explain that, although direct quotes from interviews would be used, it would not be possible to identify individual informants.

It was decided to audio-tape all interviews, for the following reason. Recording of qualitative interviews is vital in order to increase the rigour of the study and provide a more transparent process of analysis. In addition, recording and the subsequent transcribing of the interview facilitated analysis. The researcher found it easier to work with hard copies of transcripts, than rely purely on memory or field notes. She also felt that copious note taking would detract from the flow of the interview. There are, however, disadvantages and ethical issues involved with audio taping, including implications for confidentiality and anonymity (see section 4.8.2). Tape-recording also increases the formality of the interview and can be off putting to the interviewee.

All study informants were therefore asked for permission to audio-tape, and all gave their permission. Interviewees were assured that audio-tapes would be kept securely and that they would be used only for the purposes of this research. They were also assured that the tapes would be destroyed on completion of the study (Data Protection Act 1998). Only when consent had been given for tape-recording was the tape-recorder produced. A micro-cassette recorder with a clip-on microphone, which was attached to the informant's clothing, was used to tape-record (see section

4.14.4). On occasion, following completion of the in-depth interview and with the recorder switched off, a few patients brought up points that they felt were too private to be allowed to be recorded. These were not included in the data collection.

At the end of the first interview, each informant was asked if s(he) would agree to participate in the repertory grid. It was explained that the second method of data collection would differ from the first in that it was a different type of interview, different questions would be asked and it would not be tape-recorded. All nurses, and all but one patient, agreed to participate in the repertory grid. Appointments were made with nurses as soon as they agreed, while patients were given a week to reflect further on their continuing participation. This allowed patients to withdraw consent if they so wished, and, hopefully, reduced the possibility of the patients feeling coerced into participating.

The researcher then contacted each patient individually, either on the telephone or in person, to confirm consent and providing that consent was given, make a second appointment. Unfortunately, because of the frail health of the informants, the one-week gap before arranging the second interview, followed by a time lapse in actual interview, meant that some patients were either too ill (n= 6) had died (n=6) or refused (n=1) before the second interview. Patient sample attrition had been anticipated, but was of a greater magnitude than expected, given the pilot study results, the researcher's knowledge of the illness trajectory and the two-year prognostic inclusion criteria. In addition, one patient-an elderly woman of 88 who felt she was too breathless to cope with further question- refused the second interview.

4.16.2 The interview process

The researcher was able to establish a rapport with both nurses and patients early on in the interviews. This was achieved by adopting an informal style and by allowing the informant to talk by using general, open, questions. Some of the nurses, but none of the patients, knew the researcher. When the researcher knew the nurse, it sometimes made the start of the interview harder- not easier- as they already knew basic things about each other, such as name, where they worked, and whether or not they had a partner and/or children. Demographic data relating to marital status, sex,

age and qualifications (nurses) was obtained at the start of the interview with all informants. Patients were not directly asked their diagnosis at any point during the interview. This decision was taken so that patients were given the opportunity to tell the researcher what they wanted to, this protected their autonomy and fitted within a phenomenological philosophy, which allows the informant to 'tell their story'. All patients volunteered the information during the course of the interview which was then cross-checked with the referring nurse.

Both nurses and patients were asked the same questions, although the interviews were approached in different ways. It was decided to adopt a style of questioning that maintained a focus on experience in keeping with phenomenology, the principal tenet of which is that the ideal interview occurs when the interviewer's short, descriptive questions or clarifying statements provide an opening for informants' lengthier and detailed descriptions. The aim was, therefore, for the flow of conversation to be controlled by the informant. The exchange was open, with the researcher adopting attentive listening and using probes such as "tell me more about that". Key questions identified in the interview schedule (section 4.11) were, therefore, asked to address the research questions and to facilitate analysis. As in the pilot study, all the patients felt able to talk willingly about their experiences, particularly their feelings about their impending death. The interviews lasted from 25-45 minutes (nurses) and 45-90 minutes (patients).

There were some differences between the nurse and patient interviews. Once facilitated to talk, the majority of patients spoke widely about their illness experiences and sometime had to be guided back to the interview prompts. The nurses, on the other hand, were more succinct and tended to keep to the prompt questions. This may have been partly because all nurses were interviewed in their work time and in their work place, and so they were conscious of the time. In addition, although patients were particularly asked about their experiences of their nursing care they sometimes talked about experiences of their care in general, or care provided by other members of the multi-professional team, such as doctors and needed therefore, to guided back to discussing aspects of their nursing care. The nurses, on the other hand, were able to discuss nursing care more easily. Nevertheless, they did, at times, also discuss the team approach to palliative care.

Both nurses and patients were able to identify positive and negative experiences of palliative nursing care and could fairly easily recall incidents to illustrate their experiences. For both nurses and patients, occasional recall of negative experiences brought back distressing emotions. However, both nurses and patients stated that they found it helpful to talk about these experiences- something that they reiterated to the researcher when she saw them for the second time. No patient or nurse needed to be referred to an appropriate body for further support.

4.17 Reliability and validity: in-depth interviews

Rigour was given particular attention for this study, by adopting the criteria outlined below as well as incorporating Long and Johnson's 'alternative means' for establishing rigour, namely: reflective journal, peer debriefing, triangulation and audit of the decision trail. For an explanation of why a transparent rather than an intuitive process was used for this study see Chapter 3 section 3.3.2.

One method for conceptualising and explaining the interpretative process in qualitative research is to use the framework initially proposed by Guba and Lincoln in 1981 (Guba and Lincoln 1988) and later refined by Sandelowski (1986). Guba and Lincoln (1988) identified four factors relating to tests of reliability and validity (rigour) in research- credibility; fittingness, auditability, and confirmability (Table 8). The four areas are now discussed in order to demonstrate how they were established for this study.

Table 8 Comparing measures for reliability and validity in quantitative and qualitative research (adapted from Guba and Lincoln 1988 p.104)

FACTORS	QUANTITATIVE RESEARCH	QUALITATIVE RESEARCH
Truth Value	Internal Validity	Credibility
Applicability	External Validity	Fittingness
Consistency	Reliability	Auditability
Neutrality	Objectivity	Confirmability

Credibility

Credibility refers to the truth value of a study (Guba and Lincoln 1988). A qualitative study is credible when the descriptors, or interpretations of, a human

experience are immediately recognisable, by those having that experience, as being similar to their own. In other words, the findings of the study make sense. The credibility of this study was established in four ways, firstly by drawing on the researcher's own experience in this clinical area, secondly by validating the themes and theme categories against the literature, thirdly by showing the theme categories to acknowledged experts in the field and asking for their opinions and finally, by keeping a field journal, which provided material for reflection.

Another method is to return to the informants themselves with a request to read the transcripts and discuss the interpretation derived by the researcher. This was not possible in this study, as the patients were deemed too ill. For those patients who were not too ill, it was decided that they would have moved on in their 'dying journey'. To take them back would have been counter-productive and potentially damaging. Moreover, Long and Johnson (2000) assert that the results of respondent validation need to be treated with caution. It is further argued that respondent feedback can be highly problematic. For instance, respondents memory may fail, they may be uncertain of some of the non verbal cues that they may have transmitted which form part of the data, or they may deny less attractive aspects of their behaviour. In addition, each individual respondent has no true insight into the experiences of other participants.

Fittingness

Applicability or transferability in qualitative research is referred to as fittingness. A qualitative study meets the criterion of fittingness when its findings can fit into contexts outside the study situation and when its audience views the findings as meaningful and applicable in terms of its own experience (Sandelowski 1986; Guba and Lincoln 1988). The findings must, therefore, fit the data from which they are derived and be well grounded in the life experiences of the informants, reflecting both typical and atypical elements. This was achieved for this study by validating the findings with the literature and with acknowledged experts in the field of palliative nursing. In addition, the researcher reflected on her clinical expertise in palliative care and compared this experience with the findings. Validating the findings with acknowledged experts has also been described as 'peer debriefing' (Long and Johnson 2000). Peer debriefing can be achieved in various forms, such

as: discussing emerging findings with knowledgeable colleagues, presenting and defending the methods and findings of a study at national research conferences, and presenting the findings and implications to interested groups. All these factors were carried out by this researcher, for this study. The former was carried out in order to stimulate consideration and exploration of additional perspectives at various stages of the process of data collection and analysis. The latter, presenting at conferences, was conducted, as it is a recognised means of submitting the method and findings of research to other researchers, in order to invite and answer critical comment. Presenting the findings to interested practitioners offered similar opportunities but with an emphasis of the implications and relevance of the findings of the study.

Auditability

Auditability in qualitative research is used instead of the term reliability commonly associated with quantitative research, and refers to the consistency of a study (Guba and Lincoln 1988). A study and its findings are auditable when another researcher can clearly follow the decision trail used by the investigator in the study. The decision trail concerns the study from beginning to end and allows another researcher or reader to follow the progression of events in the study and understand its logic. Moreover, leaving a decision trail entails discussing, explicitly, decisions taken about the theoretical, methodological and analytical choices throughout the study (Koch 1994). Another researcher should, therefore, be able to arrive at the same, or comparable, conclusions, given the researcher's data.

This was achieved, in this research, by keeping all data collection documentation, including full transcripts and tapes safely. In addition, the researcher kept a reflective journal during data collection and analysis (see section 4.18). Moreover, the researcher's supervisors had access to the data, which was cross-checked against the findings.

Confirmability

Confirmability in qualitative research can only be established when auditability, truth-value and applicability are established. The easiest way to establish confirmability is to ask whether the study can be replicated (Miles and Huberman 1994). Confirmability does not have to be objective, as in quantitative research.

Indeed, qualitative research values subjectivity, rather than objectivity, in terms of the relationship between researcher and informant. Engagement with, rather than detachment from, the phenomena studied is sought in the interests of truth. Confirmability, therefore, refers to the findings themselves rather than the subjective or objective stance of the researcher (Sandelowski 1986). This was achieved, for this study, through leaving a decision trail (see auditabilty). Confirmability was also established by linking the in-depth interview and repertory grid data, and by using methodological triangulation. Triangulation helped to reduce the disadvantages inherent in the use of a single method (see chapter 3 section 3.5).

4.18 Data analysis: in-depth interviews

The method used to analyse the in-depth interview data in this research was as outlined by Miles and Huberman (1994). The procedure was used in conjunction with the phenomenological method described by Colaizzi (1978) (Figure 1). This method was chosen for theoretical and practical reasons. Colaizzi's framework for phenomenological data analysis uses a step by step method which proved useful for a novice phenomenologist. Although the adoption of a framework for analysing interpretative research has been criticised (Crotty 1996), this researcher believed that using a framework for analysing data for this study enhanced the rigour of the study by making the process more transparent and auditable (see section 4.17). The incorporation of the suggestions outlined by Miles and Huberman aided the pragmatic aspect of the data analysis process, such as using the contact summary sheets (Appendix IX), as well as enhancing the transparency and rigour of the data analysis.

The key feature that demonstrated that this was a rigorous study in terms of data analysis was, that it was a transparent process, with key auditable steps (see figure 1). In addition, all tapes were transcribed verbatim, allowing for deeper scrutiny both by the researcher and her supervisors if necessary. All tapes and transcripts were kept for the duration of the study. Moreover, a reflexive approach was adhered to during interpretation, which involved self-critique and self-appraisal (Koch and Harrington 1998). This fits with the purpose of phenomenological inquiry, where the researcher is very much part of the interpretative process (Koch 1994). The reflexive approach was maintained by keeping a field journal, in which the researcher was able to record

any nuances or feelings regarding the study, particularly those that occurred during data collection and data analysis. The field journal was maintained in keeping with the phenomenological method (Gadamer 1994; Koch 1994). The journal was divided into different sections to include details about: access, the research setting, experiences during data collection and issues that arose during data collection.

It was decided to analyse the nurse and patient data separately. This allowed issues from the nurses' and patients' data to be compared more easily (Table 16, Table 17). In addition, it would have been difficult to analyse the nurse-patient data in pairs due to sample attrition problems. Furthermore, because the study sites did not use primary nursing, the nurse-patient pairs were not 'true pairs'. The patients were patients that the nurses had been looking after, rather than patients that they had a 'special' relationship with.

After each interview, the tapes were listened to, and reflective notes made in relation to the raw data. The notes included comments on the researcher's relationship with the informants, second thoughts about what the informant was really saying, doubts about the quality of data, new hypotheses and mental notes to pursue an issue further in the next interview. In addition, prompts or triggers to material in other interviews were also noted.

The tapes were transcribed verbatim by a secretary employed for this purpose. Verbatim transcription was employed for practical and theoretical reasons. It was practical as the hard copies facilitated the data analysis process, by making it easier to identify significant statements, which were formulated into theme clusters. The theoretical reasons, were that the process of transcription allowed data analysis to be more rigorous, by enabling a more transparent process or be adhered to.

The transcriber was given exact instructions to type all verbal utterances precisely including '*umm*' and '*eh*'. After transcription, the researcher listened to the tapes with the hard copy to check for accuracy. At this point, stage notes were added, such as the person 'got upset', as well as significant pauses or silences in the text. The final changes to the transcripts were then made. A contact summary sheet (Miles and Huberman 1994 p.52-53, Appendix IX) was completed which noted the key themes

and a summary of the interview. This preliminary stage of analysis was carried out so that the thematic analysis could begin, and so that questions could be rephrased or omitted for the next interview

Transcripts were read and re-read. This reading of the transcripts as a whole is a hallmark of the interpretative process in a phenomenological approach (Colaizzi (1978). Understanding of the text was therefore based on an understanding of the context in which it is situated and was not taken in isolation.

A process known as extracting significant statements (Colaizzi 1978) was carried out. In other words, key information and key phrases that directly pertained to the investigated phenomena were highlighted. These were then reflected on and notes made regarding the statements, a process known as formulating meanings (Colaizzi 1978).

Highlighted information was then grouped to allow themes to emerge. Themes were identified in relation to segments of data and noted in the left-hand margin. Theme clusters were then formed into a list. Similar theme clusters were joined together. Theme clusters that were alluded to by less than three informants were removed from the list. Theme clusters always employed the words used by the informants.

The following extract (Karen, 19/E) demonstrates how significant statements were organised into theme clusters.

DEVELOPING THEMES	SIGNIFICANT STATEMENTS
Someone to talk to	I know it's sometimes impossible but a wee bit of time to sit and talk to a patient if they're upset I was really low and she came up and asked me what was wrong
Getting to know me	everybody gets to know you know how to treat you know your wee qualms know you personally
Not helping me	I lay there for three days without a wash nobody came into give me a hand she (the nurse) had me crying
Presence of nurse	she put her arms around me she just came up and sat with me - she was really good she said we are here for you

The theme clusters, which consisted of informants own words were then grouped together to form theme categories. The researcher chose the theme category titles. The list of themes and theme clusters was then worked through and repetitions or similar headings removed to produce a final list. An extract from the nurses' theme cluster list is presented in Table 9.

Table 9 Extract from nurses' theme cluster list

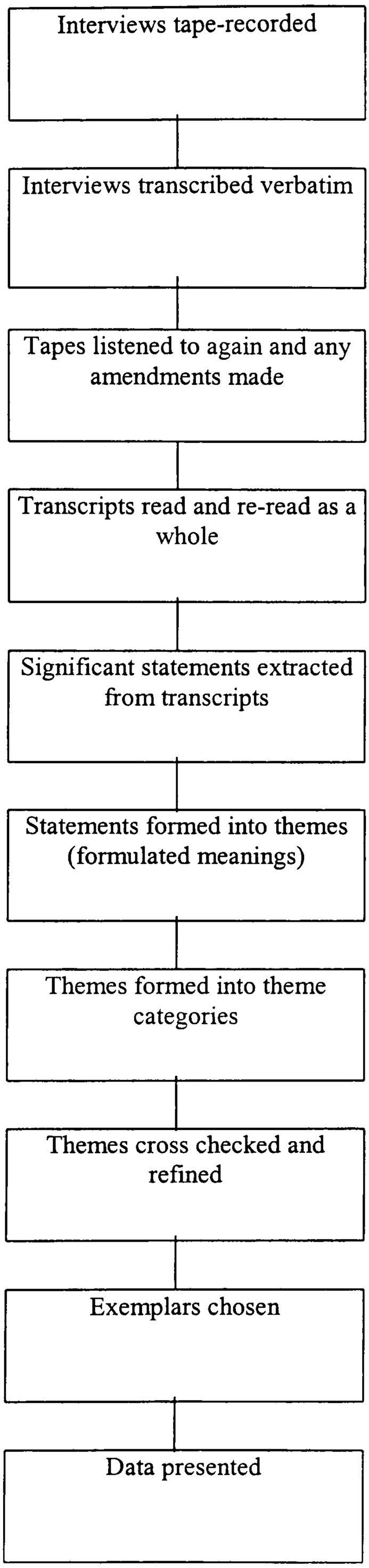
THEME CLUSTER	NUMBER OF NURSES REFERRING TO THEME
Empathetic	10
Facilitating Communication-Family or Health Care Professionals	10
Fostering Hope or False Hope	4
Good Communication Skills	9
Good Listener	9
Hospice as Home \ Family Care	9
Humour	4
Information Giving	8
Intuition	3
Knowledge \ Up To Date	14
Knows Patient \ Establishing a Relationship	14
Maintaining Independence	5
Meeting Patients Needs \ Wishes \ Goals or Not	12
Non Judgmental	2
Nothing More We Can Do	2
Pain and Symptom Control	18

It took several attempts to arrive at a final list of theme categories. The process involved eliciting the assistance of an experienced staff nurse in a hospice who helped to refine the theme categories. She also volunteered her own stories to verify both the theme categories and the theme clusters. This added to the rigour of the study. Displaying the themes in tables and concept maps further refined the data.

Conclusions were then drawn and verified by checking the findings against the literature. The final stage involved looking for patterns between the nurse and patient data, thus making contrasts and comparisons between the two sets of data.

Figure 1 depicts the process of data analysis diagrammatically.

Figure 1 - Flow diagram depicting process of data analysis



4.18.1 Use of computer software

Computer software such as NUDIST (Richard and Richards 1991; 1994) is available for analysing qualitative data, but was rejected. The justification for its rejection is explored here. Firstly, the researcher could not find a software package suitable for analysing phenomenological data. Indeed, in their search for more sophisticated technology, researchers often forget to choose a method of analysis allied to the philosophical roots and conceptual nature of their methodology. Many phenomenological researchers have been criticised for attempting to use methods of analysis derived from grounded theory which has a completely different philosophical root and social science foundation from phenomenology.

Secondly, the researcher was uncomfortable about the amount of time it takes to learn, and become comfortable with, a software programme, particularly as she was working full time during the course of the study and was not receiving funding for the research. Thirdly, the researcher was concerned about the fact that computers can limit the amount of data that can be viewed at any one time, therefore changing the data context. Likewise software programmes can also strip the context or minimise the data by fragmenting and breaking up the information, instead of maximising views or integrating the data. Nevertheless, as technology develops, a thorough and efficient method of analysing phenomenological data is much called for.

4.19 Data collection: repertory grid: process and procedure

4.19.1 The repertory grid procedure

There were some general differences between the in-depth interviews and repertory grids in terms of procedure. The repertory grid interviews were not tape-recorded. The researcher already had a rapport with the informant, so the need for general 'getting to know you' conversation was eliminated. Furthermore, the researcher had spoken to all the patients by telephone prior to conducting the repertory grids. In addition, the more structured format of the repertory grids did not allow for as much general conversation. All patients, despite being in frail health, were able to complete the repertory grid procedure and all stated that they had benefited from this experience. Some nurses reported that they found the grids to be particularly challenging, more so than the in-depth interviews. One nurse stated that it felt 'more

like a test, as if you are analysing me'. At the beginning of each of the repertory grids, all informants were reminded of the purpose of the study. Verbal consent to participate was again sought, and obtained, from all informants. In all cases, the repertory grids were conducted after the in-depth interviews. At the beginning of each repertory grid, the researcher reminded the informants of the purpose of the study and regained their consent. This was done verbally, as informants had already signed a consent form (section 4.16).

4.19.2 The repertory grid process

As outlined earlier (4.12.2), the repertory grid process consisted of three stages- eliciting elements, eliciting constructs, and completing the grid. The three stages are outlined here, according to the process carried out for this study.

Eliciting elements

Each individual was asked to name five people (elements) to whom they would turn for care, and five people to whom they would not. Informants were requested to choose people (elements) from three groups, (health care professionals, family, and friends), and to give the first name of the person, specifying whether a professional, or family, or friend. These elements were chosen in order to explore how informants perceived family/friends as carers versus professionals as carers. Each element (person) was then assigned a letter. The first five, ACEGI and the second five BDFHJ. In addition, informants were supplied with two elements 'self as I am' (K) and 'self as I want to be' (L).

Eliciting constructs

The name of each element (person) was written on a card and the cards placed on a working surface so that the informants were clear as to whom they were speaking about. Each interviewee was then presented with three of their elements in the form of a triad and asked how two were alike and different from the third. This process was repeated until all elements had been contrasted with each other. The repertory grid procedure requires that informants produce opposites, thus creating bipolar dimensions; for example, if a informant described two elements as 'interesting', then the opposite might be 'boring'. Informants were asked not to use the word 'caring',

as this was a supplied construct. This facilitated informants to explore characteristics of caring more fully.

All informants were asked, to facilitate computer analysis, to use no more than four words when describing their constructs. Of the 14 constructs used, 11 were elicited. The remaining three constructs were supplied constructs derived from the pilot study, namely, 'caring - not caring', 'someone I can talk to - someone I can't talk to', 'someone I trust- someone I don't trust' (Figure 2, section 4.14). The information was then transferred to a 12 (elements) x 14 (constructs) grid.

Completing the grid

The grid matrix now contained a list of elements along the top and constructs on the vertical axis. The researcher then asked each individual to rate each person (element) against the constructs on a scale of 1-7, with 7 as the highest. For instance, if the element was Susan and the construct 'interesting (7) - boring (1)', the interviewee would rate Susan from 7-1 according to how interesting or boring they felt she was.

The repertory grids took between 45-60 minutes to complete. At the end of the interview, each informant was thanked. However, there often followed a general discussion, during which informants talked socially about various aspects of their life. This lasted usually no longer than 10 minutes, and did not constitute part of data collection.

In addition, the fact that two interviews took place allowed a closer relationship between researcher and informant to develop than if just one interview had occurred. This sometimes made it difficult to end the interviews with the patient sample. The researcher was aware that all the patients were seriously ill. Indeed, as stated earlier, the majority of patients (n=12) were too ill, or had died, before the second interview took place. The researcher was also aware that the patients were likely to have died before the study was completed, meaning that they would never see the usefulness of their participation. Whenever the patients wished the researcher well in her studies, the comments had a particular poignancy.

After discussing her feelings regarding interview closure with the person previously identified for support issues during data collection and analysis, the researcher decided to write and thank the informants for their participation. This provided an opportunity for closure for the researcher as well as for the informants. In addition, the referring nurse made a point of informing the researcher when the patient died.

4.20 Reliability and validity of repertory grids

An overview of the literature related to reliability and validity of repertory grids is in section 3.4.3

Reliability

Measures to test reliability for grids include a test for the stability of elements and constructs. In other words, the measures determine whether the constructs and elements are representative of the sample and subject. The stability of the elements and constructs was tested for this study by comparing nurse and patient elicited constructs. All informants chose caring characteristics represented in the literature (see Discussion Chapter).

Specific relationships between constructs were tested using an established classification tool, Landfield (1971) (Appendix X, section 3.4.2, section 6.1).

Validity

Internal, construct, concurrent and predictive validity were all established in the grids. Internal and construct validity of the repertory grids was established in a number of ways. For instance, if the grid is a valid measure of personal constructs, it would be expected that its elicitation procedure would produce constructs on which elements were more highly differentiated than they were on supplied constructs, this was achieved for this study. In addition, the extremity of the ratings on the construct scales was also used as a valid measure of the importance to the subject of the construct, or of the elements rated (Winter 1992). A measure to determine the internal and construct validity of a number of grids was also used (Beail 1985), involving averaging relationship scores between constructs, rather than individual ratings.

Predictive validity was determined by the usefulness of the grids in determining caring characteristics. The constructs were compared with the caring literature in general and in particular with other repertory grid caring studies.

4.21 Data analysis: repertory grids

The method used to analyse the repertory grids in this study involved four stages- eyeballing, construct classification, analysis using FLEXIGRID and using descriptive and inferential statistics to compare grids. This procedure is based on that outlined by Winter (1992).

Each raw grid was firstly examined to provide broad information about the subject. Otherwise known as 'eyeballing' the grid, this helped the researcher to begin to understand the subject's world. For instance, Figure 2 indicates that the constructs *compassionate comes when you want them and interested in my comfort* were positive constructs in terms of caring. 'Bad carers' were seen as *lacking commitment, having tunnel vision and being self centred.* Examining the elements, and then how they are scored, demonstrated that the most important carer was *Sam.* Exploring the grid in this way also revealed how the informant rated themselves against the positive and negative aspects of caring. In the example given in Figure 2 the informant's ideal self was rated the same as her most important carer *Sam (Nurse).*

Figure 2 - Example of a raw grid

	1. A JANE family	**2. B** IAN husband family	**3. C** GILL Dr Prof.	**4. D** TIM Dr Prof.	**5. E** SAM nurse Prof.	**6. F** SUE family	**G** JO daughter family	**H** KAY friend	**I** AMY daughter family	**J** MEL nurse Prof.	**11. K SELF AS I AM**	**12. L IDEAL SELF**
1.	7	4	6	2	7	5	6	5	6	4	6	7
2.	7	7	5	1	7	3	7	4	6	3	7	7
3.	7	5	7	2	7	5	7	5	7	4	5	7
4.	7	4	5	1	7	4	5	5	6	4	6	7
5.	1	4	5	5	1	6	5	6	4	2	1	1
6.	6	4	6	2	7	3	6	4	6	2	6	7
7.	1	2	4	7	1	4	6	4	1	5	1	1
8.	7	7	6	1	7	5	7	5	7	4	7	7
9.	1	5	2	6	1	4	1	4	1	5	2	1
10.	7	5	6	2	7	5	7	6	7	5	6	7
11.	6	3	6	3	7	3	6	5	6	4	6	7
12.	7	4	6	2	7	4	7	6	7	5	6	7
13.	7	6	5	2	7	5	6	5	6	5	6	7
14.	7	3	5	3	7	6	5	5	6	4	6	7

1. COMPASSIONATE	ONLY INTERESTED IN A SUPERFICIAL WAY
2. COMES WHEN YOU WANT THEM	LACK OF COMMITMENT
3. INTERESTED IN MY COMFORT	JUST INTERESTED IN DOING JOB
4. UNSELFISH	SELF CENTRED
5. HAS TUNNEL VISION	WIDE LIFE EXPERIENCE
6. NOT JUDGING	CRITICAL
7. APPEARANCES MATTER TOO MUCH	SEES BEYOND OUTER COVER
8. GIVES SOMETHING OF SELF	WOULD CARE JUST FOR SHOW
9. LACKS TOLERANCE	TOLERATES IDIOSYNCRASIES
10. GENEROUS NATURE	UNGENEROUS
11. UNDERSTANDING	IMPATIENT
12. CARING	**NOT CARING**
13. SOMEONE I TRUST	**SOMEONE I DON'T TRUST**
14. SOMEONE I CAN TALK TO	**SOMEONE I CAN'T TALK TO**

Content analysis was then carried out by using the classification system outlined by Landfield (1971 p. 165-175) (Appendix X, section 3.4.2). Landfield's tool was is the most commonly employed system of construct classification. It was chosen for this study as the categories lend themselves to a study of aspects of caring. A reliability check was carried out by using Landfield's classification for the pilot study.

This study's constructs were further classified against the theme categories derived from the in-depth interviews in order to provide further verification of the data and also to establish the link between the two data sets.

The data were then analysed by a computer software programme, FLEXIGRID (Tschudi 1993). FLEXIGRID, as opposed to other grid software packages was chosen for practical reasons, the researcher was taught how to use FLEXIGRID by David Winter and was able to access computers with FLEXIGRID installed at the psychology department, Napsbury Hospital in England.

FLEXIGRID presents the mean rating on each construct. This is followed by the variation about the mean and this variation is expressed as a percentage of the total variation about all construct means. From the mean rating, it is possible to ascertain whether a particular construct is being employed in a 'lopsided' manner; that is, most elements are assigned to only one of its poles.

The variation about a construct mean is calculated. This is a measure of the extent to which the construct discriminates between elements and, therefore, of its usefulness. For instance, with the construct *someone I can talk to,* presented in Figure 3 below, elements are assigned to either the pole or contrast:

Figure 3 Example of part of a grid to demonstrate how a construct can be assigned to pole or contrast.

A KAY wife family	**B** SUE friend	**C** ANN Dr. Prof.	**D** PAUL Dr. Prof.	**E** JULIE Nurse Prof..	**F** FAY family	**G** JANE Nurse Prof.	**H** JO Nurse Prof.	**I** DAVE friend	**J** EVE Nurse Prof..	**K** **SELF AS I AM**	**L** **SELF AS I WANT TO BE**
7	1	7	1	7	2	7	1	7	1	6	7

The variation about a construct mean can also be used a measure of superordinancy; that is, the importance of that construct to the individual. Superordinancy is a term Kelly (1955) used to suggest that organisation of an individual's constructs is hierarchical; with some constructs subsuming others and is derived from the theoretical proposition that constructs are organised into systems. The higher the percentage of total variance score for a construct the more superordinate it is to the individual's other constructs. For instance in Josies's grid *feel comfortable with them-feel uncomfortable with them* received a score of 4.99 (% of total variance) when rated against Josie's elements where as *mature-immature* received a score of 8.61(% of total variance). *Mature-immature* was therefore superordinate to *feel comfortable with them-feel uncomfortable with them.*

A matrix of construct intercorrelations was developed which demonstrated the relationship between all the constructs. This matrix reflected the psychological relationships between constructs.

The distance between elements was then calculated, with 0 indicating that the two elements are construed in identical fashion while 1 is expected by. In this study, the distance between the informants' perception of themselves (*self as I am*) with their *good carer* and *bad carer* was calculated. The same calculation was carried out for the informants' perception of their *ideal self* with their *good carer* and *bad carer.* This indicated how the informants perceived themselves as a carer and whether they would like to be like their good and bad carer.

A principal component analysis was performed on the raw data. The higher the percentage of total variance accounted for by the first principal component, the more tightly organised and unidimensional is the individual's construing (Winter 1992). In a sample of normal subjects completing 16 x 16 grids, the mean percentage was found to be 39.4 (Ryle and Breen 1972). Winter (1992) indicated that the smaller the grid, the higher this percentage would be.

Measures of the relationships between constructs and elements were calculated. They are presented as cosines, which are equivalent to correlations and, therefore, have a range from -1.0 to 1.0.

The vectors and loadings of each element and construct on each component were performed. By plotting the loadings on the first two components, a visual representation of the individual's construct system is then obtained (Appendix XI). The plot provided a useful indication of interesting features of the grid. For instance, elements in opposing quadrants of an informant's grid are determined to be the most dissimilar. The elements that are furthest from the centre are considered to be the most extremely perceived. The plots, however, cannot be compared and are more useful for learning about an individual's grid than for comparing grids.

The most highly scored constructs for each informant were presented in a table with the mean and percentage of total variance. The constructs were then classified according to Landfield's criteria and the in-depth interview theme categories, and ranked in order of relative importance.

4.21.1 Statistical analysis

Statistical advice was obtained before commencing the statistical analysis. A disadvantage of FLEXIGRID is that it only analyses grids individually. Grouping grids was, therefore, carried out using descriptive and inferential statistics with the aid of the software programme MINITAB. MINITAB was chosen for practical reasons. The researcher was shown how to use MINITAB by the statistician approached for statistical advice for this study.

The p value was set at $p= 0.05$, and $df = 29$ $(n_1 + n_2)$ was statistically significant. The researcher initially considered analysing the data using the two tailed t-test and Mann-Whitney U test. However, due to the small sample size and the fact that the data were not normally distributed, the use of the Mann-Whitney U test was considered the most appropriate test to use.

Statistical tests used

Mann-Whitney U test: is a non-parametric test used to test the difference between two independent groups, based on ranked scores (Polit and Hungler 1999). The Mann-Whitney U test was used for this study, to compare the nurse and patient

means for each of the repertory grid results. The Mann-Whitney U test is also particularly useful when the sample size is small.

Confidence interval (CI): is a parametric test which indicates the range of values within which a population parameter is expected to lie (Polit and Hungler 1999). The CI was used for this study, in order to identify the likely size of the difference between the means of the two populations and is useful in addition to the Mann-Whitney U test (Polit and Hungler 1999). A 95% CI for the difference in means is appropriate when using the Mann-Whitney U test and therefore the CI for this study was set at 95%.

The following comparisons were, therefore, ascertained. The overall mean, median, standard deviation (SD) and standard error mean (SE), were calculated for the percentage of variance accounted for by each supplied construct in turn. A CI and Mann-Whitney U test were calculated for each supplied construct, and the findings presented in a scatter plot graph in order to demonstrate how the values for the nurses and patients compared.

The nurse and patient data for the principal component analysis were compared by calculating an overall mean, median, SD and SE. The data were also compared using a CI and Mann-Whitney U test. A scatter- plot graph was used to present the findings.

Comparisons were drawn between the two data sets for the average distance between *self* and *ideal self* and the *good carer* and *bad carer.* The overall mean, median, SD and SE were calculated for *self* and *good carer, ideal self* and *good carer*, *self* and *bad carer* and *ideal self* and *bad carer*. A CI and Mann-Whitney U test were then calculated for each component and the findings were presented in a scatter plot graph.

4.22 Overall summary

The key points identified in this chapter are that the study design used methodological triangulation with a phenomenological approach underpinning the study. The data collection tools were in-depth interviews and the repertory grid technique. In addition, the study was conducted at four study sites, two hospices and two hospitals. The sample size consisted of 22 patient and 22 nurses. The aim was for all informants to complete both methods of data collection. However, only nine patients completed the repertory grid. The issues of sample attrition in a population of dying patients are addressed. Furthermore, the ethical issues arising from the study, with particular emphasis on informed consent and confidentiality, were outlined. The in-depth interviews were designed around key areas from the literature and the research questions, in order to ascertain informants' views of good and bad aspects of palliative care and how they perceived a good palliative care nurse. The repertory grid was designed using mainly elicited constructs and elements in order to elucidate the characteristics of caring. A pilot study was conducted to test the feasibility of the study. A detailed account of how both sets of data were analysed is put forward. A rigorous, systematic approach was used in the process of data analysis. Moreover, tests for rigour, reliability, and validity were applied to both sets of data.

In the following chapter, the findings and the in-depth interviews and repertory grid results are presented.

Chapter 5 In-Depth Interview Findings

5.0 Researcher's note on presentation of findings

The findings are presented with the patients' in-depth interviews first, followed by the nurses' in-depth interviews. The repertory grid findings are presented in Chapter 6. The repertory grid findings and the links with the in-depth interview data are presented in the Discussion (Chapter 7).

In relation to the presentation of exemplars, the following typographical notes are used: missing text is indicated by ..... a gap in the conversation or a display of emotion, such as the informant getting upset, is denoted by ----.

The codes used to represent the study sites for patients and nurses are presented in Table 10.

Table 10. Informant and study site codes.

STUDY SITE	PATIENT	NURSE
Hospice A	A	B
Hospice C	C	D
Hospital B	E	F
Hospital D	G	H

5.1. Response rate

All 44 informants completed the in-depth interview. Thirteen patients did not complete the repertory grid interview for the following reasons: too ill (n= 6); died (n=6); refused (n=1). The patient who refused was an elderly lady of 88 years who stated that she felt too breathless to complete another interview.

5.2 Demographics

Patients (n=22) and nurses (n=22) from four sites, two hospices and two hospitals, participated in the study. A profile of the informants is presented in Appendix XII.

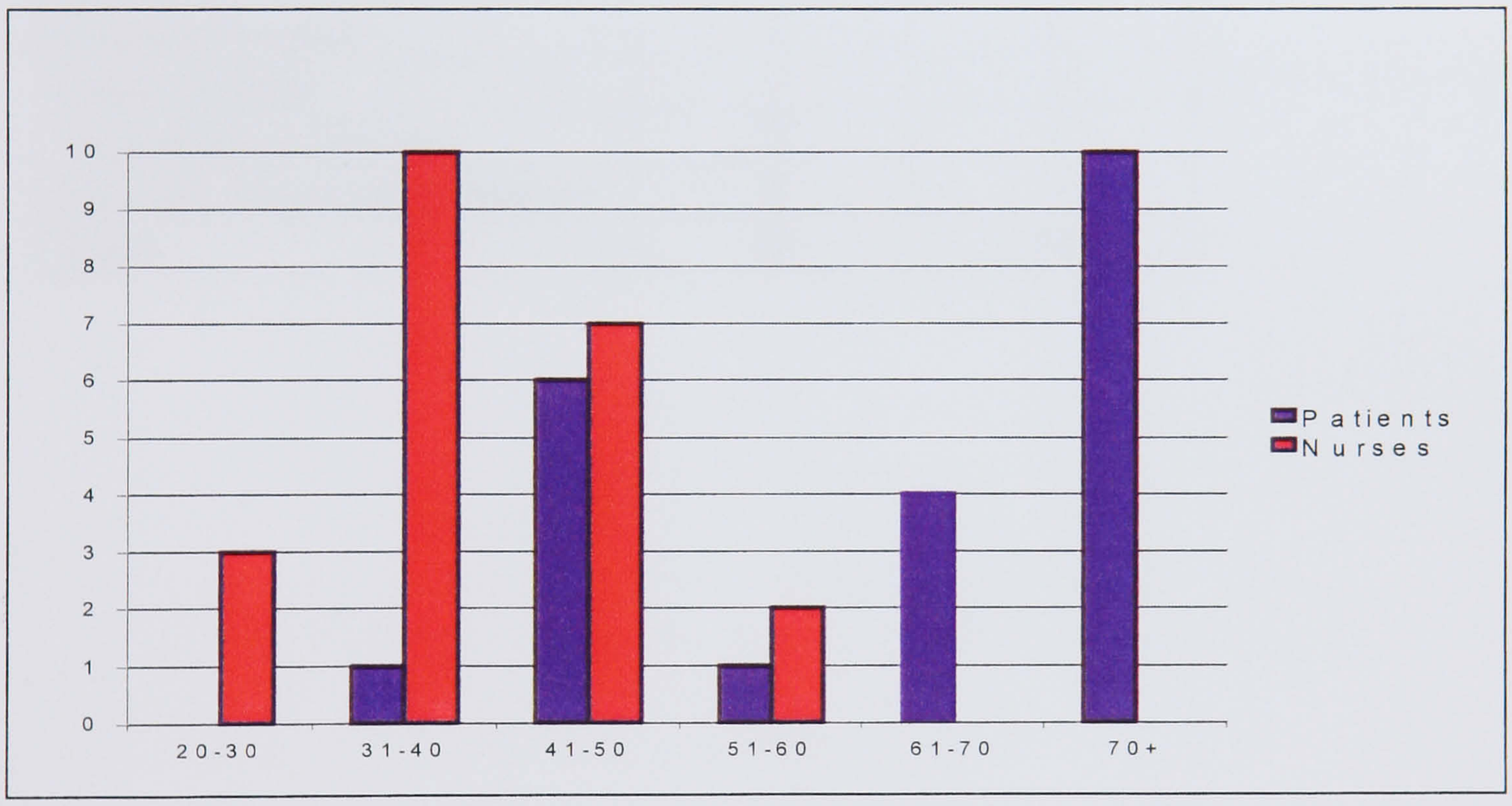
The patient sample consisted of 11 female and 11 male patients, as can be seen in Table 11 and Figure 4. Although the sample was purposive, it represents accurately the population of people suffering from life threatening illnesses (Joint report SMAC and SNMAC 1992; Eve and Smith 1996). The nurse sample consisted of 20 female and two male nurses. This reflects the small number of men working in palliative care (Hospice Information Service 1999 personal communication). The majority of patients were either married (n=12) or widowed (n=9). The majority of nurses were also married (n=16); six nurses were single. No informants stated that they were divorced. The majority of patients were over 50, as depicted in Figure 5.

Table 11 Sample demographics

	PATIENTS		**NURSES**	
	Male	**Female**	**Male**	**Female**
Sex	11	11	2	20
Hospice	11		11	
Hospital	11		11	
Marital status-Married	12		16	
Widowed	9		0	
Single	1		6	

Figure 4 Number of informants by sex and marital status

Figure 5 Number of informants by age and sample



5.2.1 Patient diagnosis

The majority of patients in this study had cancer, but five had non-malignant disease (Table 12). The range of diagnoses reflects the nature of specialist palliative care services which, more recently, have sought to admit patients with non-malignant disease, particularly neurological diseases (Addington-Hall 1998) as well as cancers.

Table 12 Diagnosis of patients by study site

DIAGNOSIS	HOSPICE	HOSPITAL
Cancer- Breast	4	2
Cancer- Lung	1	1
Cancer- Colorectal	0	2
Cancer-Prostate	3	1
Cancer-Other	1	2
Neurological Disease	2	0
Chronic Respiratory Disease	0	3
Total	11	11

5.2.2 Nurse qualifications

As indicated in the study criteria all the nurses in the study were registered nurses with a qualification in palliative care. Ten nurses had a graduate or post-graduate qualification reflecting the National Council For Hospice And Specialist Palliative Care Services (1995) guidelines which state that at least the lead professional in any team in a specialist palliative care unit should have a graduate level, or above, qualification in palliative care (Table 13). The reason that the numbers in both the hospice and hospital columns do not add up to 22 (total number of nurse informants) is that several nurses had more than one qualification.

Table 13 Nurses' qualifications by study site

QUALIFICATION	HOSPICE	HOSPITAL
Care Of Dying- 5 Day course	1	2
ENB 931- Care of the Dying	1	3
PSII - Palliative Care	5	3
PSII - Cancer Care	0	1
Post-Graduate Diploma in Palliative Care	5	4
Post-Graduate Diploma in Cancer Care	0	1
BSc With Palliative Option	1	0
Number Of Nurses With More Than One Palliative Care Qualification	2	3

5.3 Patient in-depth interviews

Four theme categories and 14 theme clusters were generated by the patient interviews, as shown in Table 14. As noted previously, all patient interviews lasted between 45-90 minutes and all patients spoke in detail about their illness and dying experiences (section 4.16.2)

The informants were identified by pseudonym. The in-depth interviews were analysed by theme category (the title of the theme) and theme clusters (sub-themes within each category), with exemplars related to each theme cluster. The theme categories are presented in order of importance for the majority of informants. The importance was ascertained by the number of patients indicating the theme and the emphasis they placed on the theme during the interview. The patients, nurses and study sites are coded, as shown in Table 10. In terms of presentation, it should be noted that each theme cluster is analysed individually with text and interpretation.

Table 14 Patients' theme categories

THEMES	CLUSTERS
Connecting	someone to talk to
	willing to listen
	getting to know me
	avoiding me
Being In Control	maintaining my independence
	fighting spirit
Meeting My Needs	not helping me
	knowing about my illness
	providing comfort
	being there for me
	spending time with me
	emotional support
Hospice As Family	making me feel relaxed
	feeling safe \ secure

5.4 Connecting

The theme category of 'connecting' was formed from the following theme clusters: 'someone to talk to', 'willing to listen', 'getting to know me' and 'avoiding me'. The theme clusters arose from prompts about describing a 'good nurse' in palliative care. In addition, 'connecting' arose from prompts about describing effective and ineffective palliative care "can you tell me about an incident that has happened to you, as far as your care was concerned, that you felt was particularly good for whatever reason?" and "can you now think of the opposite of that, an incident, which you feel, demonstrated ineffective care for whatever reason?".

'Connecting' was a central theme for both nurses and patients, as depicted in Figure 6 (section 4.13). It formed the core of how both nurses and patients viewed palliative nursing and the role of the good palliative nurse. 'Connection' implies a joining together of two or more elements, with a relationship formed between them. It therefore serves that it is an appropriate term to link the concept of interpersonal communication with the building of a nurse-patient relationship. The researcher acknowledges the influence of other researchers, when arriving at this term. These other nurse researchers, usually in studies about caring, nurse-patient relationships or spirituality (O'Berle and Davies 1990, 1992; Zerwekh 1995; Lindsey 1996; Milne and McWilliam 1996; Golberg 1998), also used the term 'connecting' as a theme in their findings.

The theme category title was chosen for several reasons. Firstly, communication meant much more to the patients than just a social interaction. Patients talked about how important communication was to their care and their dying experience, and also specified that they viewed communication as an essential part of the role of the nurse caring for them. Secondly, as communication was unravelled, all patients talked about both effective and ineffective communication issues at some point in their interview, particularly in respect of the good nurse's role or what patients considered to be effective care. The third reason for choosing the title 'connecting' was that the patient interviews highlighted the importance of establishing a relationship with the nurse prior to being able to communicate personal and deep feelings and profound

concerns. However, 'connecting' was not always effective: for example, some patients described a lack of connection in terms of being left alone or avoided.

Each theme cluster will now be explored. One or more exemplars will be provided for each theme cluster in order to illustrate the meaning of each cluster and the interpretative process arrived at to elicit the theme clusters.

5.4.1 *Someone to talk to*

The theme cluster 'someone to talk to' was an important component of communication as far as the patients were concerned. The cluster title was chosen from direct quotes from patients. The majority of patients mentioned that having 'someone to talk to' was an essential component of their care. The patients emphasised the importance of this cluster by again mentioning 'someone to talk to' as an attribute of a good palliative nurse. The theme cluster 'someone to talk to', therefore, arose from prompts asking patients to describe their 'good nurse' and their notion of effective care. They described the feeling of having someone to talk to as being an important feature of their dying experience by letting them know that they were not alone, and by being able to disclose any physical or psychological concerns they had about their illness. They felt that the nurse should not just be able to talk to them, but also should be available when the patient needed to talk. Brian typifies this in the following exemplar.

BRIAN 42/ C-: *"I think, without decrying any of the staff, I think they do need a little bit more instruction of some description as to how to talk to people. Not just people with cancer, anybody that gets serious news like that. There should be somebody---- It would not take much. There should be somebody available to be able to talk. Just someone to talk to. They don't have to be extremely conversant but I think a bit of counselling skills is necessary. Maybe they all have got this but they didn't show it to me on the day I was told my diagnosis".*

The patients wanted the nurse to be available when required. For instance, if they were upset, they wanted to know that there would be a nurse to talk to and that the nurse would anticipate their needs by approaching them directly. It was not always

necessary for it to be the same nurse but preferably an established relationship. When asked: "Can you tell me about the sort of person that you feel is a good nurse?" Tom described a nurse who helped by talking to him.

TOM 31/ E: *"One (a nurse) that can sit down and talk to you, hold your hand and give you a wee bit of confidence. Someone who would talk about you and your illness. Someone who can tell you about people who have had it and who have got through it..... Someone like that cancer nurse who spoke to me in the hospital. I mean she was really good - but that is her job I suppose. But the other nurses in the hospital, I never found one that was really good at talking to me. They were nice enough, but....."*

In the following exemplar, Anne expressed the isolation engendered by the diagnosis of a life-threatening illness and the subsequent need to talk to someone. Anne's isolation pervades this extract. Her desire represents that of many patients who want someone to talk to about their feelings.

ANNE 33/E: *"Yesterday I was low.... because I had to have chemotherapy treatment the day before. It is just me and the two kids in the house. It is just because I feel I can't talk to anybody. If I had just been able yesterday to phone up someone and say; 'look I feel really terrible'. I mean I just don't even know what to do with myself----- I just want somebody to talk to. Everybody, everybody's different, but I am sitting here. I have not even got a number. I don't even know the first place to look for someone to speak to. I feel that from that point of view, doctors or nurses should be saying; 'we are here for you'. All they do after your treatment is say: 'Keep your pecker up. On you go. Everything's fine'. When you leave there until your next appointment in three weeks time, there is just nothing----- You are not speaking about it. You are not speaking about it to anyone."*

The theme cluster 'someone to talk to' represented patients' views of the characteristics of a good palliative nurse. Many of the patients as exemplified in the extracts from Brian, Tom and Anne felt that this was a skill lacking in the nurses they had encountered.

5.4.2 *Willing to listen*

The theme cluster title 'willing to listen' was taken directly from patient quotes. 'Willing to listen' was an extension of 'someone to talk to' and arose from patients' descriptions of their good nurse. In other words, not only had there to be a nurse available, but also there needed to be a nurse who was open to being talked to. Most patients thought that willingness to listen was one of the most important skills of the nurse, and vital to the relationship between the nurse and the patient. The majority of patients identified being 'willing to listen' as a characteristic of a good nurse in palliative care. Indeed, a few patients indicated that 'willing to listen' was the most important characteristic a good nurse should have. The following exemplars illustrate this issue.

BRIDGET: "*What do you think makes a good nurse? What sort of person should they be?"*

BILL 2/A: *"Oh a listener, a listener and somebody who will listen to you and doesn't talk..... You want to talk to somebody and you don't want to have to listen to them. May I tell of an instance last night. My illness has made me very emotional. I can cry at things that in the old days I would never have cried at. I did last night, just cry. One of the staff nurses - she was extremely good. She listened to me. It made all the difference. When she went out I felt a lot better. That is what I mean. She listened....."*

BRIDGET: **"***Can you tell me about the sort of person that you feel is a good nurse?"*

JOSIE 12/A: *"Well they are always interested in you and quite willing to listen to you if you have any problems. The nurse should be willing to listen to you"*

BRIDGET: **"***Can you tell me about the sort of person that you feel is a good nurse?"*

KAREN 19/E: *"Somebody with a nice personality, bedside manner and willing to listen to you, even though you're blethering a lot of rubbish but still willing to listen to you and understand you, understand your feelings, listen to your problems,*

somebody like that. On this ward if you've got a problem they will come and listen to you and sort it out for you and they care."

BRIDGET: "*Can you tell me about the sort of person that you feel is a good nurse?"*

MARK 16/A: *"Easy going, pleasant and friendly, willing to listen to you, I think that's important, willing to listen to you."*

BRIDGET: "*Can you tell me about the sort of person that you feel is a good nurse?"*

ANN 33/G: *"I just think, for someone to sit down and listen to what I had to say for once, without butting in. I wanted someone who would understand how I actually felt".*

BRIDGET: "*What do you think makes a good nurse? What sort of person should they be?"*

EMILY 35/G: *"Just somebody who comes in and they listen to you and they are interested in you and they've got time to sit with you. That way, you know you are not on your own."*

BRIDGET: "*Can you tell me a bit about the sort of person that you feel is a good nurse?"*

SELINA 40/C: *"I would say someone that really that listens more than talks. They make you just feel that because at that moment in time they're just dealing with you. Like at Hospice X, if they have an extra five or ten minutes they could stand and chat at the nurses' station but they don't they sit at your bedside and listen to you, listen to your problems."*

All these extracts exemplify how the patient viewed a good palliative nurse. The consistent theme is that the nurse made him/herself available to the patient and was there for them when they wanted to talk. Patients, such as Bill, Ann, Karen and Selina, perceived that being a good listener involved listening without talking. Other patients, such as Josie and Ann, felt that being 'willing to listen' involved

empathising with patients and understanding how patients felt. However, patients such as Karen and Selina felt that the purpose of the nurse being 'willing to listen' was to try and find out the patients' problems and allow patients to express their concerns.

5.4.3 Getting to know me

'Getting to know me' was chosen as a theme cluster title as the researcher felt that it encapsulated the importance the patients attributed to the forging of nurse-patient relationships. This title again arose directly from patient quotes. Several patients mentioned the significance of the nurse understanding them, and getting to know them, as an important component of the nurse's role in palliative care. This theme cluster arose out of prompts about effective and ineffective incidents of palliative care as well as prompts about describing a good palliative care nurse.

Most patients spoke about the importance of developing trusting relationships with the nurses who were looking after them. Honesty was particularly meaningful. The nurse getting to know them was, therefore, an important component of connecting with the nurse. Patients did not like evasiveness or pretence. They wanted to be kept informed about their illness and prognosis.

Karen personified the importance of continuity in care when recurrent hospitalisation was required, a sense of belonging and of connecting with the nurse in the presence of a chronic illness.

KAREN 19/ E: *"Everybody gets to know you and they know your illness and they know how to treat you. They know your wee qualms and they know you personally. They take an interest personally in you as well. I just feel if I am coming here at least I know that they know what's wrong with me. Whereas if I am going to another ward they don't know me from Adam to Eve. If I take ill during the night, if I have a bad asthma attack during the night I have to go to the unit. They know what to do here. I am just rushed right down there and ventilated-----"*

The notion of understanding the patient as a person and both forming, and establishing, the nurse-patient relationship was, therefore, viewed as a significant component of the role of the palliative nurse as far as the patient sample was concerned. Patients such as Karen felt that they had more confidence and trust in the nurse if the nurse knew them and, therefore, empathised with them, understood how they felt and were aware of their particular needs.

5.4.4 Avoiding me

Sometimes, however, the connection was never established: in other words, communication was ineffective and the nurse-patient relationship was not formed. This occurred when patients felt that professionals were avoiding them. 'Avoiding me' was selected as a title directly from patient quotes. Although this theme cluster was mentioned by a minority of patients, those patients who did mention 'avoiding me' attached such significance to it in terms of strongly-worded statements and emphasis, both verbally and non verbally, that it was included as theme cluster.

In the following two exemplars, Brian and Angus describe how they were avoided by nurses after they had been given the diagnosis of a terminal illness. Both men felt let down by the nurses and they both described the incidents in terms of ineffective care.

ANGUS 44/ C: "*Well I was in hospital a fortnight after the tests and all that and I was informed it was terminal------ I was just lying in the bed there... The other patients were getting seen to and I was not..... It was not so good. There was nobody who came up to me. Nobody had a wee word in my ear ...*"

BRIDGET: *"Nobody spoke to you?"*

ANGUS*: "Oh the doctors, the consultant, spoke to me about my illness and all that. He said, 'Don't worry about it, we'll make sure you are not in pain'.... But the old type of nurse- nobody came up and sat beside my bed. It was tough you know----- Nobody really came up and spoke to me. That was like seven or eight days after I'd been told and nobody came up and said to me..... The nurses came round. The doctor came round on his rounds but he just bypassed me."*

BRIAN 42/ C: *"To tell the person 'yes you have terminal cancer', which was a bit of a shock to say the least. Particularly as they told me that there was no way I had cancer in the first place. The word was 'pancreatic cancer' and 'there is nothing we can do for you'. Well, I baffled them with my reaction by not screaming and swinging from the chandeliers or bursting into tears because I didn't know how to react. So I was stuck there, in bed, after they told me the news and I said 'well all I can do is think effective, go forward and fight'. So they were so pleased at my response. They left and it was three hours before I could really get myself together and speak to anybody in my family. I just could not contact anybody. That was the longest three hours I think I have ever had. The staff didn't know... The nursing staff preferred to hide behind the screens rather than come and say anything for fear they might upset me. Meanwhile I would rather have had a cup of tea and talk to somebody. They didn't know how to react and I didn't know how to react. I just wanted somebody to talk to---- I wanted to share my shocking news with somebody else and they just avoided me....."*

The exemplars demonstrated the importance of breaking bad news well. If the informing of a diagnosis and of a poor prognosis were handled insensitively, the way in which the 'news' was told remained with the patient. For example, patients could remember the doctor's aftershave, the date, the time and details of the event. Furthermore, bad news broken badly appeared to affect patients' adjustment to their illness, as they seemed to be unable to move on in their illness experience.

5.4.5 Summary

The theme category 'connecting' highlights the importance of the nurse-patient relationship and effective communication in palliative care. The theme clusters within 'connecting', being available to talk to the patient, being willing to listen to the patient, and getting to know the patient as a person, were all perceived to be essential components of the role of a good palliative care nurse. The isolating feature of having a life-threatening illness was also expressed in the exemplars related to 'someone to talk to' and 'being willing to listen'. Patients wanted to be able to express their concerns and share their problems with a nurse. Moreover, they wanted to connect in terms of establishing and sustaining a relationship with a nurse. They

perceived that the nurse should understand them as a person and not just treat them as an illness. In terms of ineffective aspects of communication, a few patients recounted incidents where nurses avoided them after the trauma of receiving the bad news of their diagnosis. This was a time when they particularly wanted a nurse to be there to talk to them and listen to them. The issue of breaking bad news was, therefore, a particular concern for the patients, with most of them believing that their news was told badly (section 5.3.4).

5.5 Being in control

The second theme category title arose directly from patient quotes and was used because of the emphasis they placed on being in control during their terminal illness as a mechanism for maintaining their independence and, therefore, their quality of life and well-being. 'Being in control' arose from the initial prompt "can you take me back to the beginning of your illness and tell me what happened?" Sometimes, more detailed descriptions arose from further probes such as "can you tell me how you cope with your illness?" or "who have you received support from since your illness started?" These probes only occurred if coping or support were specifically mentioned by patients in the telling of their stories.

'Being in control' was composed of the following theme clusters: 'maintaining my independence' and 'fighting spirit'. Patients wanted to be cared for and wanted their families around them. Nevertheless, they still wanted to be able to control what was happening to them. Thus, 'being in control' was something they wanted both the nurses and their families to respect.

5.5.1 Maintaining my independence

The theme cluster 'maintaining my independence' arose out of the initial prompt "can you take me back to the beginning of your illness and tell me what happened?" and the question about effective care "can you tell me about an incident that has happened to you, as far as your care was concerned, that you felt was particularly good for whatever reason?" The theme cluster title was chosen from direct patient quotes. In the following example, Sally describes the importance of 'maintaining my independence'. Despite frail health and the fact that she was dying, Sally felt that the

last remaining aspect of her life over which she had any control, was her independence. In reality, many patients did not have much independence, but it represented a wish and, perhaps, the desire, to be well, in that independence became a substitute for 'wellness'. In this short extract, Sally used the words 'in control' three times, signifying the importance of independence to her.

SALLY 7/A: *"I am quite an outgoing person and it is important that I get back on my feet. At the moment I am not so well-----. Anyway at the moment it is horrible----- ----. It is important - well it makes me feel I want to get back in control. That is the way I feel. I feel as if I like to be in control of myself. Since I have been ill my family are all trying to help, but I feel myself, I want to be in control."*

Mhari tried to remain in control until her death, which occurred four days after this interview. This was despite the fact that she was bed-bound and paralysed with spinal cord compression and so lacked independence in the conventional sense. Patients like Mhari, who are more or less totally dependent, can maintain their independence by remaining in control. This may be in terms of decision-making or choices about their care and quality of life. Mhari sat up in bed and dictated who should come into her room, at what time she should have her meals and her personal hygiene needs, and who should visit. For Mhari, being in control influenced her quality of life and allowed her to cope with day-to-day living.

MHARI: "*I was in control totally up until maybe a week or two ago. Last week it seems that I was completely out of the game for three days or so. But apart from that, I am now very weak but I am still in control...*"

In the following exemplars, Hilary and Jerry personify a group of patients who were ill, but not facing impending death. Independence was important to them, but not so central that it dominated their quality of life, probably because they had not yet lost their independence. These patients saw their loss of independence as a significant factor in their dying experience. They coped by remaining in control and clinging on to what independence they had left.

HILARY 13/E: *"Well I have not exactly had much luck lately. I am not unhappy about it but I can see it is the best solution (coming to live with her daughter) but I would prefer to have been independent....l I feel a bit useless and feel I have given everything up really."*

JERRY 15/A: *"I make all my own meals. I only have a meal with my family, any of my family, once a year - that is Christmas day. I go to my daughter's home. Every other time I make all my own meals, do my own washing, do my own shopping and I am going to as long as I am going to be able to do it..... I mean I don't like to be a nuisance to my family. I look at it this way - I have had my life and - I mean my family are just having their lives and I would not impose one wee bit. The first three months after I lost my wife they couldn't do enough for me. I got it into my head, I said 'look' - talking to myself - I said 'it's about time you were getting up off your backside and getting on' and I did and I learned a lot...."*

'Maintaining my independence' appeared to be more important to those who were dying than those who were ill, but not dying. This may have been because independence was the last vestigial of having had an independent life. They were dying, they knew they were dying and yet, rather than give up, they harboured a profound desire for independence. It allowed them to feel a sense of well being and contributed to being able to handle their impending death.

5.5.2 Fighting spirit

The theme cluster title 'fighting spirit' was chosen from direct patient quotes and arose from the initial prompt "can you take me back to the beginning of your illness and tell me what happened?" Several of the patients appeared to maintain their control by adopting a 'fighting spirit' and thinking effectively about the future. This seemed to be their way of coping with their terminal illness. For instance, the fight against cancer took over Joe's life and he focused all his energy on it. He 'knew' that thinking effectively was the only way for him to cope with his diagnosis.

JOE 11/A-: "*You see my wife has had fifteen years of cancer too. We've fought cancer, each of us has been in the fight - against cancer,.....We are fighting cancer*

because well it has to be, because it's the only way - to beat cancer - cancer will not be done just sitting in a chair. You've got to be a patient who moves - keeps moving..."

Conversely, Selina believed that saying you were fighting cancer was unhelpful. She believed all individuals cope in their own way and should not have a way of coping imposed on them. She described her anger when she read a newspaper article about fighting breast cancer.

SELINA 40/C: *"The Daily Record did an article on breast cancer. It was by the women's editor in the Daily Record. It was about this friend of hers who had just developed breast cancer and she was not going to let it get her down. She was going to fight it and she was going to be all right because she was going to fight it. That was the whole tone of the article. I mean I never 'phone about anything in the papers, but the whole tone in the article was this girl's going to fight it so she is going to be all right. But Joe Bloggs next door, who died tragically from breast cancer, it was obvious she hadn't fought enough. That was the sort of tone and it really really annoyed me because I have lost a lot of good friends who fought a lot harder than me. At that time it hadn't come back, it was not secondary. I was OK at that time, so I phoned up and I really ladled into her."*

BRIDGET: *"You actually got to speak to her?"*

SELINA: *" She said to me; 'I really didn't mean it like that, I was trying to just put the effective thing'. I said; 'It is important that you do fight it but you really shouldn't have...'. I mean it was a real insult to other people who have lost wives and mothers and sisters and girlfriends through breast cancer. Are you trying to tell me they that they wanted to die? That they didn't try and fight the disease? I said, 'You'll need to put something in to counteract this' and she promised she would, but she never did, she never did. She said, 'Well I'll come out and let you have your say', but she never did that either. It was terrible, terrible, I said 'that is a shame' I said, 'a whole double spread on breast cancer and you've not got one helpful thing in there to help women who are going through the disease'. I said, 'in fact you've done more damage than help'. But I never ever heard anything else."*

5.5.3 Summary

Being in control was an important aspect of maintaining and enhancing the patients' quality of life which enabled them to cope with their dying experience. The patients were of the opinion that it was part of the nurse's role in palliative care to help them to maintain this control and independence. A particularly interesting issue here was the importance that patients attributed to maintaining their independence, even when they appeared to be at their most dependent.

5.6 Meeting my needs

The theme category of 'meeting my needs' was formed from the following theme clusters: 'not helping me', 'knowing about my illness', 'providing comfort', 'being there for me' and 'supporting me'. The theme category label 'meeting my needs' was chosen by the researcher as it encapsulated what the patients were saying about how they wished care to be provided by nurses in palliative care. The majority of patients described the importance of the nurse 'meeting their needs', 'being there for them' and 'respecting their wishes' at some point in the interview. 'Meeting my needs', together with the theme of 'connecting', encompassed how the patients described the role of the nurse in palliative care. 'Meeting my needs' arose out of the patients' descriptions of a good nurse as well as their scenarios of effective or ineffective care. 'Meeting my needs' was, therefore, not always viewed as effective by the patients, and subsequently involved both helpful and unhelpful activities.

5.6.1 Not helping me

'Not helping me' was chosen as a theme cluster title directly from patient quotes and arose from prompts about describing incidents of ineffective aspects of the patient's care. Some of the patients, when describing examples of ineffective care, recounted examples when nurses had not helped them. Although not all patients mentioned the nurse not helping them, those who did remembered the incidents so clearly and attributed such significance to them, that the researcher decided to included them in a theme cluster. These incidents involved scenarios where physical aspects of care were poor or inadequate, although they were often coupled with aspects of poor communication (section 5.3.4). Karen recalled vividly an incidence of ineffective

care following a severe asthmatic attack. She felt let down by the nurse when she was at her lowest ebb and most dependent.

KAREN 19/E: *"I was in Ward X - a year past January. I was very bad with asthma. I was taken straight to the intensive care unit. It was pneumonia that I had. I was ventilated for eight days and when I woke up, I didn't even know where I was. I had no power on my right side or anything because some of the muscles seized up. I was taken to Ward X. I never normally go there. I always come to this ward. Anyway, I lay there for three days without a wash, without getting my nightie changed. My sister came in and she went off her head. The nurse told her they would get somebody to help her give me a wash. But nobody gave her a hand. She did it herself, washing me and all that. I mean your wee sister coming in to wash you------- The next day the nurse, I will not mention names, came in and she said; 'what would you like to do madam?'; 'who do you think you are, the Queen?'... She had me crying------ I was unable to walk, I could not even - I am left-handed so I could not even feed myself. I could not hold a glass in my hand. Nobody came in to give me a hand, nobody helped me."*

Karen felt let down by the nurse's behaviour, which she perceived as unhelpful and personified ineffective care.

Emily described what she felt to be ineffective care when in hospital recovering from a mastectomy. She believed that her physical care was neglected. Emily was left to manage her activities of daily living when she felt that she could not cope. She believed that the nurse should have anticipated her needs. However, at no point did she tell the nurses she could not cope. Emily also described a nurse whom she felt provided the opposite of her previous experience by anticipating her needs and solving her problems, as well as providing a link between the GP and the patient.

EMILY 35/G: *"In the hospital I had my dressing on my wound after the breast operation. They changed the dressing when I had the operation on the Thursday and then again on the Saturday. Then they didn't look at it again, they didn't come and check my wound. I thought they would have checked it every morning to see if it was*

OK. They didn't check it and they were going to send me home with the same dirty bandage on until one of the staff nurses, who comes from round here, said; 'oh no we are not sending you home like that Emily'. I mean the care just was not there. In the hospital two days after the operation I went for a bath, and the bath was up on this huge big stool and there was only a little stool to stand up on. They let me go in and out of that bath and didn't help, didn't come to see if I needed help. There was just this 'didn't care attitude' about it. Even when you go back to the hospital for check ups you are in and out and they don't care. There just is not the care that I have had since X (the Macmillan nurse) came. She puts you right. If anything is wrong she does not let you suffer. She is right on to the doctors and gets you a prescription, no matter what it is....."

The patients who described incidents where they perceived the nurses' behaviour as unhelpful indicated that helping was a key characteristic of a good palliative care nurse. Therefore, when the nurse did not help them, for whatever reason, they felt let down and perceived that their care had been ineffective

5.6.2 Knowing about my illness

The theme cluster 'knowing about my illness' was chosen as a title directly from patient quotes. The theme cluster arose out of patient descriptions of a good palliative nurse as well as descriptions of incidents of effective palliative care. In order to meet their needs, several of the patients expected the nurse to know and understand their illness. They believed that nurses who lacked knowledge or information about their illness were detrimental to their care. Karen felt that, generally, nurses knew very little about asthma, particularly chronic asthma, which carries a poor life expectancy. She thought that it would make a difference to her care if nurses were to specialise in asthma and subsequently provide her, and her family, with the appropriate advice and support.

KAREN 19/ E-: "*Sometimes I think, with asthma like I have, I think a lot of the nurses were not brought up to date on it. A lot of them don't know about it. I mean a lot of people say, 'oh it is asthma; they can't breathe that is it'. But it is a dangerous thing. I think a lot of the problem is that half of them don't know what*

an asthmatic is going through. I mean it is just like somebody choking you to death, that is what it's like. You get a lot of people who are ignorant, even ordinary people. I am not just talking about nurses and doctors. I mean ordinary people who are ignorant about asthma. I have been in the hospital once before when a lady said, 'oh she has just got a touch of asthma, look at her lying there'. I had just come out of the unit. I had just been ventilated. So I mean people are ignorant about it and so are a lot of nursing staff because they have not been trained up on it."

BRIDGET: *"Do you think they should be?"*

KAREN: *"I think so, because I mean asthma is just as bad as cancer and AIDS. They are all brought up to date on all that, so why not asthma too? It is just recently that you are getting to hear about asthma. Going back years ago it was never heard of as much. I just feel they should have a couple of days course on asthma and chest people like me. That would give them a rough idea of what they are dealing with. Some of them don't know. I have heard someone say, 'oh breathe slow, breathe slow'. You can't, you are trying to get a breath of air and they are telling you to breathe normally. You just can't do it. It is impossible- those are the people that are really not up to date on asthma and chest conditions."*

Karen made a pertinent point when she stated that 'asthma is just as bad as cancer and AIDS'. It is often perceived that patients view cancer as the worst possible diagnosis. In addition, there are increasing government resources attributed to preventing and treating cancer. Yet Karen, like other patients with non-malignant disease, felt that her care was under-resourced not just in terms of treatment and care but also in terms of nursing knowledge. She believed that nurses were not educated in asthma. Furthermore, she had not received care from a specialist nurse since her diagnosis, something she probably would have done had she suffered from cancer.

5.6.3 Providing comfort

'Providing comfort' arose out of patients' descriptions of a good nurse. Several patients talked about the nurse being able to meet their needs physically for them. They often referred to this as 'comforting'; hence the title 'providing comfort' which was chosen by the researcher to encapsulate this description of comfort as a caring

activity. This comfort was usually in terms of attention to detail and helping patients with the daily activities that they were unable to do for themselves. Several patients expected the nurse to be able to provide comfort and meet their needs by being able to solve, as well as anticipate, their problems, such as the need for pain relief or knowing they needed someone to be with them. Selina described how she considered providing comfort as an important part of the role of the nurse in palliative care. She thought that comfort involved the nurse paying attention to detail. She felt that her needs were met in the hospice and was impressed with the willingness to provide care and attention by the nurses that she encountered.

SELINA 35/ E: *"The nurses at the hospice just generally make you feel that although there may be loads of other people, they are just dealing with you. Although, you know they are not, they make you feel that at that moment in time they are just dealing with you. They say things like 'are you sure the bath is hot enough'. They pay attention to every single wee detail, things that people have not done for you for years. You know that they are checking everything out. They just generally just seem to care beyond caring really. They are also doing extra things, like the aromatherapy and all that. They don't need to do these extra things..."*

5.6.4 Being there for me

'Being there for me' emerged as a theme cluster from patients' direct quotes and arose from patients' descriptions of a good palliative nurse and their descriptions of incidents of effective palliative care. 'Being there for me' emanated from the importance the patients attached to the presence of the nurse, particularly when they were feeling low or upset. Patients assumed that the nurse would be able to anticipate when they needed someone there for them. Several patients described how merely the presence of the nurse made them feel comforted and supported. The nurse was there for them in a variety of ways, such as letting them know they (the nurses) were available, spending time with patients and explaining how the patient could contact the nurse when they were not there. This was particularly important to the patients when they were at home.

In the following exemplar, Elsbeth recounted how the nurse anticipated that she would need someone to talk to after she had been told her diagnosis and that the nurse merely being there enabled her to feel comforted and supported.

ELSBETH 14/E: "*Well, it is not a very nice thing to be told, is it? (That she had liver cancer). Dr X came in to tell me the news- I was alone of course - and It is not a very nice thing to be told that you have maybe months left to live. I was very touched that afterwards, one of the nurses, I can't remember who it was - she was very thoughtful indeed. She came and sat by me and chatted. That was thoughtful, very good. I must say I was very touched by her timing of such a thing.*"

The exemplars in this section indicate a lack of equity in practice in terms of 'being there for the patient'. As stated earlier (section 5.3.4), some patients described incidents when they were avoided or ignored after they had received the devastating news of their diagnosis, whereas some nurses seemed to be able to anticipate the patient's needs at a crucial time. Others, on the other hand, ignored the patient's needs or chose not to display warmth and empathy. The helpful or effective aspect of being there is demonstrated in the following exemplar. Karen described how the presence of the nurse helped her when she was feeling particularly low. She thought that the nurse was there for her, and reassured her.

KAREN 19/E: *"There was one time I was really low. I was sitting crying and it was the nurse who's on today actually. I was sitting really breaking my heart and she came up and asked me what was wrong and put her arm around me. I just said; 'I just feel nobody wants to know what's bothering me today'. She said 'that's not true'. It wasn't true but that's how I was feeling. So she just put her arms around me and made me a cup of tea and sorted me all out. She said 'nobody disbelieves you, don't be so silly'. I was thinking that everybody was thinking I was putting it all on and nobody wanted to know me. It was really a busy ward and I had been in for a while and they were attending everyone else. I just felt I was getting neglected, but I wasn't. I thought that they were not wanting to know me. It is just how I was feeling and she came up, she stayed with me, she reassured me, she really was good...."*

5.6.5 Spending time with me

'Spending time with me' was chosen as a theme cluster title from actual patient quotes. This theme cluster arose from patients' descriptions of effective or ineffective incidents of palliative caring. Several patients took the issue of 'being there' further. They felt that time was an important element in the nurse being able to meet their needs. The 'busy' nurse, or being in an in-patient unit that was busy, made the patients feel unwelcome and made it difficult for them to ask for help. For instance, Bill thought that there was a difference between how much time the nurse spent with him in the hospice in comparison with his recent hospital experiences.

BILL 2/A: *"I have not been in hospital much during my life. I have been very fortunate but recently, because of this illness I have now more to do with nursing staff, community staff and it is nice to be able to talk to somebody knowing you are not going to be interrupted all the time. I know they don't have the time but some nurses have a knack of having all the time in the world - but I know they don't have - but they have this knack and that is the difference between a good nurse, especially here (in the hospice)... on this whole ward - even when they are busy, they spend time with you. That is why we're put here (in the hospice)."*

In the following exemplar, Lee, who had chronic respiratory disease and was often hospitalised, described how he felt that the nurses did not have enough time to spend with the patient. He recounted that the time when he most wanted the nurses' support was when they were rushing around or busy with other patients.

LEE 29/ E-: *"I think they (the nurses) don't have enough time to spend with you. I mean when they're so busy, especially in Ward X, the receiving ward. They don't really get to know the patients because they're in and out so often."*

'Spending time with me' was an important theme clusters as far as the patients were concerned, as indicated in the exemplars above. Patients such as Bill and Lee felt that, in their experience, nurses were working under pressure. The patients were particularly aware of this in the hospital and community settings. They were aware (Bill's exemplar) that the hospice has a higher nurse-patient ratio. The patient

sample felt that, when the nurses did make time for them, they were able to establish a better relationship with the nurses and their needs were more likely to be met.

5.6.6 Emotional support

'Emotional support' arose out of patients' descriptions of a 'good nurse' in palliative care and when 'telling the story' of their illness and dying experience at the beginning of the interview. The theme cluster label was selected from actual patient quotes. Several patients described their illness as having emotional as well as physical components. Subsequently, they felt that the nurse should have been able to support them emotionally. They believed that this was an essential component of the nurse in palliative care, and important in terms of meeting their needs. For instance, Emily thought that breast cancer was more of an emotional that a physical disease. She wanted support from a nurse who was caring, compassionate and empathetic.

EMILY 35/ E: *"In the hospital it is different because they don't have the time, we know that. I would say you have to have nurses who are specialised in that treatment especially for a breast operation. They just don't know what to do. They are just going about their ordinary business and the running of the ward. Yet sometimes you need treatment that is a little bit special, especially at that time when you are in the hospital and having the treatment. I don't just mean to be treated in a special way but just to be treated a little bit differently in certain aspects of that care……you should not be treated like it is varicose veins, because it is different. I mean it really is different. It is different to have breast cancer. All the women are the same, you have this fear at that time that you are going to die. So you need somebody who has that little bit of compassion. Someone who would buck you up a little bit. They need to know how a patient feels so they can see the other side of it. They probably don't know. They are just doing the nursing and they are looking after your wound or whatever but they probably don't know the emotional side of it."*

Emotional support did not necessarily have to come from the nurse. Several patients described how they would have liked to have support from other patients suffering from the same disease as them. They described how isolated they felt and how

devastating they found being given a diagnosis of, and living with, cancer. They thought that speaking to someone who had been through a similar experience about their fears would have helped them. For instance, Anne described how she wished she had known about a support group for patients with breast cancer when she was first diagnosed. In the second exemplar, Emily, who also had breast cancer, recounted how she wished she had had support from other women with the disease.

ANNE 33/G: *"That is something I would really have liked to have had someone to talk to, someone else who has been through it, another woman. I am sure there must be a support group or something like that for people like me. I feel sometimes I have been a kind of isolated case in all of this...."*

EMILY 35/E : "*I feel really strongly about that. I feel that I would like to be able to help somebody the way that I would have liked to have been helped. I mean, if they'd given me a list and they said well there are girls who are willing to come out and speak to you or 'phone them. If I didn't want to phone them I didn't need to phone them. At least I would have had had a list of somebody I could phone. Because I felt that it was a death sentence, I mean, that fortnight before I went into the hospital, I am not joking, it was a nightmare. I would not like to go through that again because I had myself buried in the cemetery, I had myself dead...."*

Receiving support was, therefore, a meaningful aspect of how the patients viewed their nursing care. This support was required particularly for the psychological or emotional aspects of the person's disease. Several patients, although interestingly mainly female patients, indicated that they would have liked to have received support from other patients with the same disease and going through similar problems to themselves.

5.6.7 Summary

The theme category of 'meeting my needs' encapsulated a major aspect of how the patients perceived the role of the nurse in palliative care. Patients were of the opinion that the supportive role of the nurse encompassed aspects of providing physical comfort as well as providing emotional support. The emphasis patients

placed on psychosocial, as opposed to technical, care is fairly unusual (discussion section 7.4.8) as far as general caring by nurses is concerned. The patients may have rated psychosocial care as a more important attribute of the palliative nurse because of the nature of their illness and the fact that they knew they were dying. When they were frightened, or wanted someone to be there for them, it was not important whether the nurse was technically good at her job or s(he) could set up an IV appropriately. It was more important that s(he) was kind, warm, compassionate, empathetic and supportive. When patients discussed the physical caring aspect of the role of the nurse, it was in terms of proving comfort by anticipating, as well as meeting, their physical concerns. When the patients mentioned the nurses' helping role, it was largely when they felt that nurses had been unhelpful by perceiving that aspects of their care had been neglected, such as helping them with activities of daily living when they were unable to do these for themselves.

5.7 Hospice as family

'Hospice as family' was chosen by the researcher as a theme category title in order to encapsulate the importance hospice patients attributed to the atmosphere, safety and sanctuary of the hospice environment. No direct question was ever asked about the role of the hospice in patients' lives. However, it became apparent when patients were describing incidents of effective care or from the initial prompt can you take me back to the beginning of your illness and tell me what happened? that the role of the 'hospice as a family' was important to them. Thus, this theme category was formed from the following clusters: 'making me feel relaxed' and 'feeling safe and secure'. The patients were of the opinion that the hospice in this respect was very different from the hospital where they had been in-patients. Indeed, those patients interviewed in the hospital setting who had never been a hospice in-patient did not recount incidents of 'feeling safe and secure' or comment on the atmosphere of the hospital. This, therefore, seems to be a concept that was unique to the hospice setting. The following exemplars therefore comprise only hospice patients' comments.

5.7.1 Making me feel relaxed

'Making me feel relaxed' as a theme cluster title was selected from actual patient quotes and arose from the prompts about describing effective or effective incidents of

palliative care. All the hospice patients in the study sample described the influence of the hospice on their well-being. While it is acknowledged that one of the major roles that a hospice fulfils is that of sanctuary, nevertheless, for this group of patients, the hospice meant more than sanctuary. The hospice was seen as a place of comfort, of security and of hope. It provided a refuge in that there were no expectations on patients for them to feel, or to behave, or to display, anything other than what they wished to. In other words, the hospice provided an enormous sense of relaxation and allowed patients 'just to be'. Several patients also talked about how much more informal and friendly the hospice was than the hospital settings that they had encountered during their illness careers.

JOE 11/A: **"***This hospice here is, I just don't know how to tell you - it is so wonderful..... Let me try and put it into words. Everybody from the nurse - the nurse right up to the Board of Directors is known by their first name. You are on first name terms."*

BRIDGET: *"Why is that important to you?"*

JOE: *"Well, it helps to relax the patient. I think that is a very important item as far as the patient is concerned, that you are in a relaxed situation. From all the way down the ladder there's no one higher or lower than the other. I also feel safe here (at the hospice), safe and happy. That is a big thing in itself. Happy and relaxed. I have all the professionalism and the comfort, the people, the professionals can give me....."*

BRIDGET: *Did that take a while to come or did you feel that when you* **...**

JOE: *I felt it immediately when I came in the door.***"**

5.7.2 Feeling safe and secure

'Feeling safe and secure' as a theme cluster arose out of patients' descriptions of effective palliative care as well as the initial prompt "can you take me back to the beginning of your illness and tell me what happened?" When telling their stories the hospice patients often recounted how their perceptions of hospice care changed when they entered the hospice for the first time. They discussed how they perceived that, when they were particularly ill or when their family needed respite, they chose to enter the hospice as an in-patient.

The following extract is an example from a young woman (42 years) with a terminal diagnosis of breast cancer. Selina was not the typical hospice patient in that she was younger and had been undergoing curative treatment. It was the pain physician who had suggested that she might benefit from hospice care in terms of providing her with respite. Although one of the roles of the hospice is to provide respite care, this is usually interpreted in terms of providing respite for the family. In Selina's case, respite was for her. She was young and was dying; she had two teenage children and a husband with ME. She needed some rest and space.

SELINA 40/C-: *"I was in a lot of pain. I had gone to the pain clinic to try and control it with different drugs. The doctor there said 'why don't you think about the hospice, going there for a while? It is not a prison. You can come in and try it and if you don't like it you can go home'. It is difficult for me. My husband has ME so one minute he's OK and the next minute he's not good. I could feel really ill but I would have to struggle to do something. He's no help to me, but I can't manage and I didn't want to go into hospital. So, I went into the hospice for the first time and it was so very restful, so comfortable and lovely to be in without being too ill. I don't mean it was over the top. I felt really safe there. The staff - nothing was a problem for them. They would do anything for you, anything. They sorted me out. I had a rest and I felt so much better..."*

5.7.3 Summary

In this study, all hospice patients believed that the hospice was the safest place for them. It may not have been the place in which they would have chosen to die, but nevertheless, they felt safe, secure and comfortable. It is interesting to note that hospital patients did not describe or use the same terminology in discussing effective care. The theme category of 'hospice as family' encapsulated how patients understood the role of the hospice in maintaining their quality of life. They welcomed the homely atmosphere and the security and safety. This notion of sanctuary seemed to capture the experience of hospice care for these patients.

Overall, the patient in-depth interview findings have encapsulated how the patients coped with their terminal illness ('being in control'), how they viewed the role of institutions in providing palliative care ('hospice as family') and how they viewed the role of the palliative nurse ('meeting my needs', 'connecting'). This combination of aspects of palliative caring, therefore, represents the patients' dying experience. Key messages which are raised as discussion points are the importance the patients attributed to the nurses' good communication skills in establishing and sustaining a relationship with the patient, the significance the patients placed on the nurse spending time and being there for them, and how s(he) should help to meet their needs by providing comfort and emotional support. The patients also placed much emphasis on the psychosocial aspect of the palliative nurses' role, which they believed was an vital component of palliative caring. The patient sample also emphasised the need for the nurse to understand them and get to know them as a person.

5.8 Nurse in-depth interviews

Four theme categories and 15 theme clusters were developed from the nurses' interview transcripts as shown below (Table 15). Although the interviews were analysed independently of the patients' interviews, some similarities were found, notably in the area of 'connecting' and, in particular, the nurses' interpersonal skills. (Figure 6, section 5.13)

Table 15 Nurse theme categories and theme clusters

THEMES	CLUSTERS
Connecting	willing to listen
	facilitating communication
	providing information
	barriers to communication
	building rapport
	spending time with patients
	supporting the patient and family
Providing Comfort	keeping patients comfortable
	controlling pain and symptoms
Working Together	teamwork
	acting as a go-between for the patient
	professional knows best
Knows What They Are Doing	learning about palliative care
	professional experience
	personal experience

5.9 Connecting

'Connecting' was chosen as a theme category title as it had many parallels with the corresponding theme in the patients' theme categories, namely, the issues of the good palliative nurse being willing to listen, as well as spending time with patients and building rapport with them. The same title was, therefore, chosen (section 5.3). It was felt that, although the theme clusters in the nurse interviews were different from the patient interviews, they still embodied the issues of interpersonal skills and the establishment and maintenance of the nurse-patient relationship. The theme category of 'connecting' was formed from the following theme clusters: 'willing to listen',

'facilitating communication', 'providing information', 'barriers to communication', building rapport', 'spending time with patients' and 'supporting the patient and their family'. The significance of 'connecting' to the nurses can be noted by the number of prompts issues arising from 'connecting'. For instance, 'connecting' arose from the prompts:

- can you think of an event where you were directly involved which you feel epitomised effective palliative care?
- can you now think of the opposite of that, an incident, where you were directly involved which you feel, demonstrated ineffective palliative care for whatever reason?
- can you describe to me the sort of person that you feel is a good palliative care nurse?

The nurses felt that communication was an essential aspect of building the nurse-patient relationship and central to their ability to provide effective care. 'Connecting' was placed first as a theme category due to its attributed importance. All the nurses talked about effective communication and establishing a relationship with the patient at some point in their interview.

5.9.1 Willing to listen

'Willing to listen' was chosen as a theme category title from actual nurse quotes. This theme cluster arose from the prompt "can you describe to me the sort of person that you feel is a good palliative care nurse?" 'Willing to listen' was the most important component of connecting as far as the nurse sample was concerned. This was determined by the number of nurses who mentioned 'willing to listen' as a characteristic of a good palliative nurse, as well as the number of nurses who mentioned this first in their description of a good palliative nurse. The most important feature of 'willing to listen', as far as the nurse sample was concerned, was that the palliative care nurse should make time to listen to patients. Sandra and Linda personify this in the exemplars below.

SANDRA 8/B: *"Well from my personal point of view of view, I think a good nurse in the hospice is a nurse who listens more than anything else. She listens with perceptive ears and with thinking and with her mind. She's not just hearing words,*

she's hearing emotions, she's hearing facial expressions. She's hearing the things that are not being said."

4/B-LINDA: *"I find sometimes when you're chatting with people, at the end of the conversation they say 'thanks very much for your advice nurse'. You really haven't given any advice. I mean you've just sat there and listened to what they've said. Actually in a way they are sort of complimenting themselves because they talk things through and they come to decisions on their own.."*

'Willing to listen' was perceived by the nurse sample to be an essential characteristic of a good palliative care nurse. They believed that patients appreciated it when they made an effort to listen to them. The nurse sample advocated that listening was an active process, which involved being perceptive as well as listening to what patents don't say as well as what they do say. This indicates the importance placed on the acquisition of and use of interpersonal skills by nurses.

5.9.2 Facilitating communication

'Facilitating communication' was chosen by the researcher as a theme cluster title to reflect how the nurses were describing their role in terms of allowing patients to talk about their feelings, as well as by acting as a mediator between patients and their families to encourage communication and 'open awareness'. 'Facilitating communication' arose from the prompt "can you think of an event where you were directly involved which you feel epitomised effective palliative care?" Similar to being 'willing to listen', was the fact that several nurses thought that a central aspect of their role in palliative care was the ability to facilitate communication. By allowing and enabling patients to talk, nurses were able to encourage patients to cope with their illness. In addition, interaction occurred more easily between staff and patients if the nurse facilitated communication. Once open communication had occurred, patients were more likely to receive support both from staff and family members, as exemplified in the following two extracts.

SARAH 22/H: *"I allowed the patient to talk, to let me know what his views were, to find out what he understood or how he interpreted what the surgeon had said.*

Basically we were able to work out between the two of us what he could achieve. That's really through skills that I've partly picked up through experience as well as through doing a communication skills course. He certainly was a bit more effective about things, although still realistic, but he had something to look forward to."

KATH 28/H: "*When the patient came into the ward I kept thinking he's actually going to get worse and he's actually going to die quite soon and nobody's really been honest with him. I thought that there's going to be things that he wants to do and say if he had that knowledge. So I actually spoke to his partner quite honestly about how I actually felt. I think that she realised that he wasn't getting better. He was now asking questions about why he wasn't getting better. After I had told his partner what was really happening, she asked me to come with her when she went to speak to him. So we both broke the news together."*

This theme cluster shows that by allowing patients to talk, nurses are providing more effective care. In addition, by acting on their intuition in terms of what the patient knows, or, more importantly, wants to know about their illness, nurses are able to facilitate truth-telling- allowing a patient to die without 'unfinished business'.

5.9.3 Providing information

'Providing information' as a theme cluster was selected from direct nurse quotes and arose from the initial prompt "can you start by telling me what you think effective or good palliative care is?" as well as nurses' descriptions of effective care "can you think of an event where you were directly involved which you feel epitomised effective palliative care?" Several nurses considered that 'providing information' to patients and keeping them informed about what was happening to them was central to providing effective palliative care. They believed that it was part of the role of the nurse to update patients about their care and treatment and that the nurse should be honest when doing this. The nurses perceived that communication broke down, and barriers were built up, if patients were not informed. Furthermore, the nurses indicated that patients were not able to make informed choices about their care and consent to treatment if they were not informed. Lisa and Gillian personify the issue of 'providing information' to patients in the following two examples.

LISA 10/B: *"We want to encourage open communication, so nobody feels that you are hiding something from them. We should try to make sure that we can spread the same amount of information around everybody. Patients themselves also need an opportunity to feel comfortable, so that they can ask questions. If they've got specific questions you need the right information for them. You need to know that if you don't feel you can answer them there is always somebody else who feels they can put them in the right direction."*

GILLIAN 36/B: *"I think that the nurse that is there at the time (when bad news is broken) has to be well informed of what's available and make this information known to her patient. It should be written down on leaflets, because people don't absorb information given to them. If they're being given bad news, that's enough of a shock, at the time they hear that, and they hear no more...."*

Both Lisa and Gillian show the need for truthfulness in their exemplars. They also indicate the need for equity in the amount of information that is given to patients, particularly at the time of diagnosis. This does not, however, take into account the individual nature of patients and the fact that some people require lots of information about their illness and care and some require little, preferring to be left in the dark.

5.9.4 Barriers to communication

'Barriers to communication' was chosen as a theme cluster title to encapsulate nurses' descriptions of ineffective communication when something- a 'barrier'- caused communication between the nurse and patient either to break down or not occur, in the first place. 'Barriers to communication' arose from the prompt "can you now think of the opposite of that, an incident, where you were directly involved which you feel demonstrated ineffective palliative care, for whatever reason? Several nurses described incidents where they felt that communication was ineffective. They believed that barriers to communication included the patient being in denial, the patient being angry and the patient being withdrawn. The nurses believed that trying to communicate with the angry or withdrawn patient, or the patient in denial, was a challenging, but important component of their care.

However, they did not all always put 'barriers', such as a patient being angry, into the context of how different individuals cope with the diagnosis of a life-threatening illness and their impending death. For instance, Jack recounted an incident that he perceived was an example of ineffective care. He described a patient who was in denial about her illness. Jack thought that he had failed somehow in his patient's care because he was unable to get the patient to open up about her feelings

JACK 1/B-: "*This particular patient had had further chemotherapy, which had no effect apart from making her extremely unwell. It had no effect on her tumour or on her symptom management. She wanted to go for more chemotherapy. I felt we had failed in a way because I felt she wasn't able to discuss it with us. I think a part of it was her denial of the fact that she wasn't going to get any better. I felt we had failed in a sense because she didn't feel comfortable discussing it openly with us. She was angry at the fact that her tumour wasn't getting any better and she wasn't getting any better. I don't think she was angry at us but I felt we had mishandled that in a way.*"

Jack's comments could, however, be perceived as naïve. The patient may have chosen to cope with her terminal illness by denying the severity of her illness. Indeed, it could be argued that Jack would have been showing more skill by allowing the patient 'to be'. Many of the nurses believed that they had failed if patients did not talk about their illness or discuss their feelings about dying. However, patients may have chosen not to talk. Moreover, patients may not have opened up because they were not given the opportunity by nurses who used avoidance or blocking tactics when the patient wanted someone to talk to (5.3.4).

Similarly, Jenny recounted a situation that she found difficult to handle, in coping with a withdrawn patient.

41/D- JENNY: "*....A patient we had in the hospice recently, she had psychological problems. She was really withdrawn. She just clammed up. She wouldn't talk to anyone. I think as nurses we should able to recognise that it's nobody's fault, that's the way the patient wants it. You have to accept it. That can be very difficult.*"

Jenny's impotence is particularly apparent. She felt inadequate by being unable to intervene, although she was experienced enough to recognise that sometime nurses need to 'stand back'. Other nurses described how they felt themselves to be failures when they were not able to help patients. Nurses may feel more valued and more competent when they are able to help patients, especially in a physical or 'doing for' way.

5.9.5 Building rapport.

The theme cluster 'building rapport' was formed from questions about the role of the nurse in palliative care and from questions about incidents of effective care. The theme cluster title was chosen from actual nurse quotes. The majority of nurses described the importance of building a rapport with the patient before effective communication and effective care could occur. The nurses also believed that they were unable to establish a relationship with all patients, and that this was something that patients thought as well. This is exemplified in the following extract.

LINDA 4/B: *"I think I've got a good rapport with this lady. I feel like that because her husband was in the hospice as a patient. I suppose that because she feels comfortable with me she spoke a lot to me. However, I'm realistic enough to know that that doesn't happen with everyone who is in the hospice. There are certain members of staff who will strike up a rapport with certain patients and families. It's not that you don't get on with them, but the family feels more comfortable with particular nurses. Other people and their family - and it tends to be if you've been the nurse admitting the patient- tend to think I'll talk to this nurse in particular."*

NICOLA 25/H: *I think you've got to try and empathise with the patient. You've got to try and think how they feel, especially in a busy ward setting...*

Nicola epitomised what several of the nurses were saying- that in order to build up a rapport with the patient, you needed to try and understand what it was that they were going through.

Some of the nurses also indicated that the use of humour was an important part of building a rapport with the patient. For instance, Fiona thought that humour was a significant aspect of connecting with the patients by providing a relaxed and warm atmosphere.

FIONA 39/D: *"I think to be a good nurse in palliative care humour is really important. I think patients really appreciate humour. I think it's important to get on with the person. It really helps when establishing a relationship with the patient."*

Nurses such as Nicola, who worked in a busy acute ward setting, indicated that balancing the needs of acutely ill patients with dying patients sometime hampered 'building a rapport' with dying patients. The hospice nurses, as indicated in Linda's extract, also recounted instances of 'building a rapport' with patients. They tended to recognise that they had more time than their hospital colleagues to build a relationship between patients and their families. Both hospital and hospice nurses however insisted that 'building a rapport' and being empathetic were essential aspects of the palliative nurse's role.

5.9.6 Spending time with patients

'Spending time with patients' was selected as a theme cluster title from actual nurse quotes. It arose from the prompt asking patients to describe a good palliative care nurse and from examples of ineffective care with the prompt "can you now think of the opposite of that (example of effective care), an incident, where you were directly involved which you feel demonstrated ineffective palliative care, for whatever reason?" Most of the nurses were of the opinion that spending time with patients was central to building a rapport and to being a good palliative nurse. They thought that this was particularly important when other professionals were not spending time with patients, as Gillian recounts in the following exemplar.

GILLIAN 36/B "*I think patients will talk more freely to nurses sometimes. Some doctors are available and make themselves available but a lot don't. The patient sees him as a very busy man, it's a very busy clinic and they don't like to ask questions. Or they do ask questions and they don't get answers. The next person*

they're going to turn to is the nurse and that nurse has got to be available for that patient and have the time for them. A good palliative care nurse should never ever give the impression that she's busy. She has got to have all the time in the world and I think that's where it all evolves (sic) round and what makes a good palliative nurse."

Nicola spoke about the importance of spending time with patients and anticipating when the patient wants to talk. She also emphasised the importance of not making false promises to patients and not leaving them in 'limbo' waiting for a nurse to talk to them.

NICOLA 25/H: " *I feel patients see nurses running around and they're maybe frightened to say things to them. You've got to give them the time and you've got to make time for them. You need to put time aside so that they get a chance to air any problems that they have. Sometimes they're frightened to say anything because they see you're busy. I think it's important that you don't rush around and you do give them the time to express views..... It's difficult sometimes but I think you do have to. As long as you set yourself time aside. If they do ask you something when you are at a busy point, as long as you do tell them that you will come back and you do go back. As long as you don't give them false promises 'oh I'll be back to see you later' and you don't go back. I think that's important because that happens a lot in nursing. You say 'oh I'll be back in five minutes' and five minutes is five hours"*

Conversely, most of the nurses described not spending enough time with the patient as an example of ineffective care as typified in the next extract. Toni thought that in her unit when time was short, it was extremely difficult to balance the needs of acutely ill patients with terminally ill patients.

TONI 37/F: *"I think time is important around here, in my setting (a busy care of the elderly ward). It's very busy and we are often trying to struggle with the needs of someone who is acutely ill versus someone who needs time spent on them because they are terminally ill..... I think we do terminal care in this particular ward, but I think there's things about it that we could do better. For instance we're very good at*

the comfort issues, for someone lying there and they're semi-conscious with a diamorphine syringe driver. Nobody really spends time with them. Somebody will go and give a freshen up, do all the hygiene bit and will do mouth care and catheter care and eye care - all these specific rituals. But then that's all they do, then they leave the patient. They could spend time - even if it was only another ten minutes after that - or they could take longer when they're doing the task so that patient gets a bit more quality care, rather than a ritual."

Several nurses in their descriptions of incidents of ineffective care recounted this lack of time and the burden it placed on nurses. Nurses who wanted to spend time with the patient, and could not because they were short staffed or under pressure, felt particularly guilty; indeed it appeared to cause them distress.

5.9.7 Providing support

The theme cluster 'providing support' arose out of questions about the role of the good nurse in palliative care and was selected as a title from direct nurse quotes. Some of the nurses thought that this was an integral component of the nurse's role. For instance, Linda utilised her personal experience to enable her to reflect on the type of care that she was able to provide to patients and their families. Similarly, Liz described how she provided support to an elderly patient on her ward. When discussing the notion of 'providing support', the nurse sample discussed how important it was to include the family in the dying patient's care. They also described how both the patient and their family needed support when coping with the patient's impending death.

LINDA 4/B: *I think the recent experience I've had personally is that sometimes in an acute setting, the family role is taken away. It's like the person becomes the property of the hospital, the medical staff and the nursing staff and the family is not included in that. I think here in the hospice we include everyone, we include the person, sons, daughters, mothers, fathers, aunts and uncles. We always allow an opportunity for any member of the family to come and speak with us. At the end of the day a lot of our patients come in for symptom control and they will go home*

again and they'll go home to the family looking after them, not us. You've got to be involved with the family, to give them the support they need.

Despite Linda's statement regarding hospital nurses' lack of involvement in caring for the family, Liz, a hospital nurse, describes an incident that demonstrates the support that she was able to provide to a patient and her friend in the last stage of her life. It also shows how caring involves using the nurse's gut feeling to provide a type of care that is, perhaps, something that would not normally be provided.

LIZ 18/F: *"I remember last year we had a lady who was admitted here. She was admitted really to die with us. She had severe liver failure. She had never been married but she had this very very good lady friend. They were just inseparable. When this particular patient was admitted, her friend came up to the ward and you could see how anxious she was. She realised that things were coming to an end. She said that her friend was very anxious and didn't want to be alone. She knew she was dying, she was unconscious. I got the vibes from her that she really wanted to stay with her. So I said to her 'do you want to stay'. She said 'oh can I, oh great, I never thought that I would be allowed to stay'. So, therefore she did - she stayed right with her, right to the end. The patient had no pain or anything like that, it was a peaceful death. All the staff spent a lot of time with her friend. She wasn't like a husband or a wife, but she was a loved one and they spent time together even at the end. I felt at the end of that, that things had gone well there.*

The issue of 'providing support' to the patients and their families was, therefore, seen as an integral part of the role of the nurse in palliative care. The nurses perceived that this support was in terms of nurses allowing the family to spend time with their dying loved ones, providing the opportunity for family members to talk to nursing staff by making themselves available, and enabling family members to care for their loved ones at home, if they so wished. The nurse sample felt that the role of a good palliative nurse was not to 'take over' the patient's care but to facilitate the family to provide care for the patient by supporting them so that the patient could die at home if they so wished.

5.9.8 Summary

The theme category of 'connecting' highlighted an important component of how the nurses perceived their role. The nurses were of the opinion that being able to communicate effectively with patients, and subsequently connect with them, was a fundamental aspect of delivering effective palliative care. They felt that nurses should be able to be willing to listen as well as be able to provide information to patients and their families. They believed that the nurses' role involved facilitating communication between patients and their families, which often involved being honest with them. They stated that their role involved encouraging patients to open up and talk about their feelings and concerns. The nurses discussed communication situations which they found difficult to handle, such as coping with denial, anger and the withdrawn patient, where the connection was not established. The nurses emphasised the importance of forming a trusting relationship with dying patients as well as trying to understand what they were going through. The majority of nurses expressed the importance of the nurse in spending time with patients. This has profound implications for staffing levels and the organisation of nursing care when patients are dying, particularly as most nurses thought that not enough time was spent with patients. The nurses believed that the use of appropriate humour, as well as providing support to patients and their families, were also important aspects of connecting with patients.

5.10 Providing comfort

The second theme category was composed from direct nurse quotes and was elicited from the prompts of

- can you start by telling me what you think effective or good palliative care is?
- can you think of an event where you were directly involved which you feel epitomised effective palliative care?
- can you describe to me the sort of person that you feel is a good palliative care nurse?

The fact that 'providing comfort' was elicited from three of the main prompts indicates the importance which the nurse sample attributed to the role of the nurse in 'providing comfort' to dying patients. 'Providing comfort' consisted of the following theme clusters: 'keeping patients comfortable' and 'controlling pain and symptoms'.

When describing issues of 'providing comfort', the nurses largely referred to the physical caring, or 'doing for', aspect of the nurses' role in palliative care. Many of the features of 'providing comfort' were considered unique to the role of the nurse in palliative care, such as aspects of 'keeping patients comfortable', possibly because of the close relationships that many nurses formed with dying patients.

5.10.1 Controlling pain and symptoms

The theme cluster 'controlling pain and symptoms' was chosen from actual nurse quotes and was elicited from the prompts

- can you start by telling me what you think effective or good palliative care is?
- can you think of an event where you were directly involved which you feel epitomised effective palliative care?
- can you now think of the opposite of that, an incident, where you were directly involved which you feel demonstrated ineffective palliative care, for whatever reason?
- can you describe to me the sort of person that you feel is a good palliative care nurse?

The fact that this theme cluster arose from all the main prompts, and was alluded to by nearly all the nurse sample, indicates the significance of this issue.

The nurse sample were of the opinion that being able to control pain and distressing symptoms was the most important component of providing comfort to patients. The nurses found it particularly distressing when patients suffered because of poorly managed symptoms. This is personified in the following exemplar. Kath felt that she had let the patient, and the other staff on the ward, down by not controlling the patient's pain adequately.

KATH 28/H: *"I felt with this patient that her pain was very badly managed. It wasn't badly managed from the point of view that we weren't trying, we did try. We had actually asked advice from the hospice. She actually died in agony. The night before she died she was actually screaming. Overnight we managed just to sort of flatten her. She died eventually quite quietly but I just felt for days that we hadn't*

managed her pain. I just felt so awful. I felt, we all felt, we had failed her in some way."

Kath indicated the view of many of the nurses that, if they were unable to control the patient's pain or distressing symptoms, they had somehow failed and inadequately fulfilled their role. Many of the nurses provided examples of inadequate, or poorly controlled, pain or symptoms as their example of ineffective palliative care.

Conversely, Nicola discussed an incident where she felt the patient's symptoms were well controlled.

NICOLA 25/F: *There is one patient I remember in particular, she had cancer of her liver and she was really quite poor when she was brought in to hospital. She was constipated, she was nauseated and she had a lot of pain. She wanted to go back home again and we didn't think it was going to be possible. However, we got all her symptoms under control and we managed to get her home for a couple of weeks. She died at home and we brought all her symptoms under control. She actually went out better than when she came in. She died peacefully at home and we managed to achieve what she wanted.*

The nurses felt their care was effective when they had been able to achieve good pain and symptom control. Providing effective pain control may satisfy the nurses' need to 'help' patients. It may also tie in with the increasing emphasis on the medicalisation of palliative care, where patients are often treated more vigorously then they were in the past. As palliative care becomes recognised as a speciality in its own right, more emphasis is placed on controlling pain and symptoms and developing new drugs and techniques for controlling pain and symptoms.

5.10.2 Keeping patients comfortable

The theme cluster title 'keeping patients comfortable' was chosen from actual nurse quotes and was formed from the prompts "can you think of an event where you were directly involved which you feel epitomised effective palliative care?" and "can you now think of the opposite of that, an incident, where you were directly involved

which you feel demonstrated ineffective palliative care, for whatever reason?" Several nurses thought that this was an important component of their role and that providing comfort was often an under-rated element of their care. 'Providing comfort' incorporates aspects of the nurses' 'doing for' role. Many of the nurses argued that 'keeping patients comfortable' was an integral part of their role, and one in which they felt that they were able to make a difference to patients' quality of life and quality of dying. For instance, Beth described how she was able to keep patients comfortable. She believed that by paying attention to detail and sorting out relatively minor comfort issues, then bigger problems did not seems as bad.

5/B- BETH: *"There's one thing that epitomises effective palliative care for me. It's a very very small incident but I just thought at the end of it, I thought that is what it's all about. In fact I decided to write it up as a reflective incident for PREPP. We had a patient in the hospice and they just weren't comfortable. She had had a bad night's sleep. She was sitting in a chair, she was reasonably comfortable in the chair but - say perhaps 80%, but she was very tired. She wasn't happy to go back to bed because she wasn't comfortable in bed. We managed to persuade her to try to go back to bed. We then got her sorted out with various types of pillows, various kind of things like that, and actually got her very comfortable. She slept for two and a half-hours in the afternoon and at the end of the afternoon she felt rested and the fear of going to bed and not being comfortable had been eased. I know it's very very small and it doesn't involve anything really, but I actually thought that improved my nursing care..... There is so much technology around now, but at the end of the day it's the right kind of pillow or the right kind of bed that really counts. It's the small things when you're in hospital that really bug you, the constipation or you can't get a drink or you can't reach the bell or whatever. They're really the things that you remember, that you get out of all perspective. So I suppose that palliative care really is 'if you can attend to small things, the big things take care of themselves."*

Beth's assertion that 'if you can attend to small things, the big things take care of themselves' may appear naïve. Moving a pillow, for instance, may not reduce despair, fear or suffering. She, like many of the other nurses, perceived that attention

to detail does make a difference to the patient's quality of life. Without a doubt, Beth's intervention did, in the above excerpt, make a difference to the patient's care and quality of life.

Amanda considered that keeping patients comfortable should be seen in the broadest sense, such as helping them to adjust to their surroundings and keeping their surroundings as much like home as possible.

3/B- AMANDA: "*I think that keeping patients comfortable is important. It means that they're not intimidated by their surroundings..... We should try and make the patient's surroundings as much like home as possible.*"

Many of the nurses interviewed believed that the 'doing for' role of the good palliative nurse was under-rated. They believed that other professionals, in particular, did not understand this aspect of the role of the nurse. Furthermore, they indicated that they perceived that 'keeping patients comfortable' made a fundamental difference to the dying person's care and well-being.

5.10.3 Summary

The theme category 'providing comfort' encapsulated the 'doing for' aspect of the nurses' role. The nurses thought that they were able to provide comfort by attending to detail. They also believed that controlling distressing pain and symptoms was an essential component of their role. They described the sense of failure they felt when they were unable to do this. Together with having good communication skills (section 5.8) and possessing knowledge and experience (section 5.11), controlling pain and symptoms was the other aspect of the role of a good palliative nurse alluded to by nearly all the nurse sample.

5.11 Working together.

The theme category 'working together' arose from the following theme clusters: 'teamwork', 'acting as a go-between for the patient' and the 'professional knows best'. The theme category title was selected to represent the number of nurses who

discussed issues of teamwork and professional working practices at some point in their interviews. This theme category was formed from the prompts

- can you start by telling me what you think effective or good palliative care is?
- can you think of an event where you were directly involved which you feel epitomised effective palliative care?
- can you now think of the opposite of that, an incident, where you were directly involved which you feel demonstrated ineffective palliative care, for whatever reason?

'Working together' indicated that the majority of the nurses from both hospice and hospital settings were of the opinion that working as a team was an integral part of providing effective palliative care. The nurses felt that those practitioners who chose to work in isolation could not provide effective care. The nurse sample also believed that it was in the best interests of patients and their families if all health care professionals were working towards achieving the same goals. When there was a dispute in goals or treatment, or a breakdown in communication between the professionals, ineffective care occurred and, ultimately, it was patients who suffered.

5.11.1 Teamwork

The theme cluster 'teamwork' was chosen from actual nurse quotes and arose out of questions about incidents of effective and ineffective palliative care (prompts, section 5.11). Several nurses described incidents where they believed either that teamwork had contributed to effective palliative care or that a lack of teamwork contributed to ineffective palliative care. This is encapsulated in the following exemplars.

24/H- ALISON: "*I think to have effective palliative care you need a team of people who believe in palliative care. I always think that that's quite difficult in the hospital setting that I work in. Sometimes I would say that patients are treated aggressively when really they should be palliative. Obviously, if the medical staff continue with treatment, that is difficult, especially when I don't agree with it. I think if you've got a team who believe in palliative care then it makes all the difference.*"

30/H- SAM: *"I think that for effective palliative care to occur the team needs to work well together. For instance, in an incident that I can think of the team worked*

well together and the patient got her wishes. She was visited regularly by the doctors. We all worked as a team. Any problems were dealt with speedily, if there was a pain problem it was dealt with and it was reviewed, as things should be."

38/D- EMMA: *"To me effective palliative care means team work - all working together to meet the needs of the patient. It is not one person working in isolation but a team working together."*

Some of the nurses believed that for effective palliative care to occur the nurses should not work in isolation, but in conjunction with their health care colleagues. This is exemplified in the following extracts.

BETH 5/B: *"I find it difficult when nurses perceive themselves as multi-disciplinarians. It's really good for the patients to see different professionals, like the doctors, the ministers and their social workers. Also it is good for them to see the manicurist and the hairdresser. Even just the day-care drivers who have brought them in the past and have now become friends. I think that's all tied up in the fact that the nurses tend to have a lot of the 'doing for' aspect of palliative care, but neither other people nor we should stop at that."*

36/F- GILLIAN: "*I think palliative care is all about good teamwork. Not just from one person but I think from the whole health care team, as well as anybody else that needs to be involved in that patient's care. I don't think that one person can do all the care for the person. I think everybody should work together and overlap, there shouldn't be distinct lines. We should all be able to work together to give that patient and family the support that they need."*

As indicated in the exemplars above, several nurses believed a good nurse should not work in isolation and that effective palliative care depended on good teamwork. Many nurses argued that the nurse was pivotal in the multi-disciplinary team and, therefore, should function as the key worker for that team. They believed that when the nurse did not act as a key worker, teamwork, particularly in the community setting, often broke down.

5.11.2 Acting as a go-between for the patient

'Acting as a go-between for the patient' was elicited as a theme cluster from direct nurse quotes. This theme cluster arose from the prompts "can you think of an event where you were directly involved which you feel epitomised effective palliative care?" and "can you describe to me the sort of person that you feel is a good palliative care nurse?" Acting as a go-between or advocate for the patient with other professionals was, therefore, perceived by the nurse sample as another significant aspect of teamwork. This is exemplified in the following exemplar.

8/B- SANDRA: *" I think generally in hospitals it's said that nurses are closer to the patients than other professionals. I think that's true, too, in the hospice. It does tend to be the nurse that patients and relatives are ready to open up to. Perhaps they feel safer with the nurse or maybe they think they're not as professional or as intelligent and feel that they can ask silly questions. I think the nurse is a facilitator, s(he) is a go-between. That's how that patient and relatives see her. I think their role is different in that way that s(he) can be the go-between between the patient and their doctor."*

In the previous exemplar, Sandra recounted how she felt that the patient felt closer to the nurse and that this was why the nurse acted as a go-between between the patient and the doctor. Furthermore, 'acting as a go-between for the patient' was a feature of the nurse's role that occurred only when good communication and established nurse-patient relationship were present.

5.11.3 Professional knows best

The theme cluster 'professional knows best' was chosen to represent the number of nurses who recounted incidents of a breakdown in communication between team members and incidents where the professionals decided on care issues without discussing them with the patient or other members of staff. This theme cluster arose from the prompt "can you now think of the opposite of that (effective care), an incident, where you were directly involved which you feel demonstrated ineffective palliative care, for whatever reason?"

Several of the nurses described incidents where professionals did not work together in the best interest of the patient. This tended to occur when the patient's wishes were not met or the professionals made decisions regarding their care such as telling the family the patient's diagnosis before telling the patient. This is exemplified in the following two extracts where the nurses recounted incidents in which the patient's wishes were not met.

22/H-SARAH: *"This patient wanted to go into a nursing home and be looked after. She was eighty-six, she'd had a hard life, she lived alone and that's what she wanted. We got her home, despite what she wanted. She's now home but she's really very unhappy, she's quite depressed, she's now not looking after herself. That's the only way that she can make us see that she doesn't want to be at home. I think, did she have to get to that point, could we not have done what she wanted?"*

36/F- GILLIAN: *"I find it very very difficult to understand why, but you'll always find that there are those nurses that say '**my** patient this' and '**my** patient that'. Control has then gone away from the patient. I just think it's very sad, I don't think as nurses or as medical professionals we have that right to take over people's lives in any way. I think that we cannot take over their lives. The patient has got to lead their own life. Maybe they're not doing or using what we feel is available but I think they still have to be in control. We have to let them be in control. But let them know what is available".*

The exemplars from Sarah and Gillian discuss incidents where control has been taken away from the patient. They indicate the patriarchal nature of health care where doctors and nurses decide on care issues 'in the best interest of the patient' without considering or ignoring the patient's true wishes.

5.11.4 Summary

The theme category 'working together' encapsulated the opinion from the nurse sample that multi-disciplinary care was a hallmark of effective palliative care. The role of the nurse as a facilitator or advocate between the patient and doctor was

recounted. The issue of how ineffective care can occur when professionals are not working together in the best interest of the patient was also discussed. The majority of nurses were unhappy when the wishes of the patient were not met. This often put them in a difficult situation with colleagues- who thought that they knew what was best for the patient. This has implications for offering patient centred care.

5.12 Knows what they are doing.

The theme category 'knows what they are doing' was formed from the prompt about describing a 'good nurse' in palliative care "can you describe to me the sort of person that you feel is a good palliative care nurse?" This theme category was selected from actual nurse quotes. 'Knows what they are doing' was composed of the following theme clusters: 'learning about palliative care', 'professional experience' and 'personal experience'. The nurse sample was virtually unanimous in indicating that having knowledge and experience were pre-requisites of a good palliative care nurse. The majority of these nurses indicated that good palliative care nurses should have a good knowledge of pain and symptom control and be able to recognise, and know how to treat, distressing symptoms. Some of the nurses indicated that good nurses needed knowledge of social and interaction skills. Several of the nurses suggested that nurses needed to acquire their knowledge of palliative care via training and courses. Nevertheless, a few nurses used the term 'well educated' when describing a good nurse in palliative care. Several nurses proposed that a 'good nurse' in palliative care must be willing to pass on their knowledge to other practitioners. One nurse mentioned that when she first started in palliative care this was how she picked up her knowledge.

The majority of nurses interviewed discussed the need for professional experience as a characteristic of a 'good nurse'. A third of the nurses also mentioned that they felt that their personal experience of death and dying had made them a better nurse and more empathetic to the dying patients they were looking after.

5.12.1 Learning about palliative care

'Learning about palliative care' was selected as a theme cluster from direct nurse quotes and arose from the prompt "can you describe to me the sort of person that you

feel is a good palliative care nurse?" This theme cluster encapsulated the nurses' descriptions of palliative care knowledge that they perceived were essential in order to be a 'good nurse' in palliative care. Most nurses maintained that the palliative care nurse should have a wide-ranging knowledge of their specialist area. They particularly mentioned knowledge of pain and symptom control as well as knowledge of communication and interpersonal skills, pharmacology and side effects of drugs and treatment. Some of the nurses indicated that nurses should have knowledge of the pathology of a patient's disease process. The following exemplars are a representation of the majority of the nurses' opinions about what a good palliative care nurse needs to learn about.

LINDA 4/B-: *"I think a good nurse in palliative care is one that always strives to become well educated because the more knowledge they have, the more they can formulate ideas and opinions. Whereas if you've got a fixed ideas, you only go down this one path. You can't think objectively. However, if you've got a wide area of knowledge and you're willing to listen to people, I think you can offer a more structured opinion about things."*

KATH 28/H: *"I think the nurse should learn about palliative care. They should be knowledgeable about symptom control, and pain. They should know what drug to use for nausea. Even just simple things like constipation, they should know what is available and what to do. I think we're getting better at it and I think that we're much more aware of what's on the market and what's helpful."*

TONI 9/F: *"I think we should we should learn about palliative care generally. I think they (a good palliative care nurse) need to have a good insight into current forms of treatment. I think we should have an understanding of the disease process to a certain extent……"*

Several nurses suggested ways in which the nurse could learn about palliative care. These suggestions included training in palliative care, attending specialist courses and generally keeping up to date. This is illustrated in the following exemplars.

LIZ 18/F: *"Well I think you can become a good nurse by taking part in courses that are specific to palliative care, with people who are experts themselves, tutors or whatever, that are experts in palliative care.*

AMANDA 3/B: *"I think you learn about palliative care probably just by looking at the different ways that you can improve the care that you're giving, either through working elsewhere or through doing courses or through reading."*

Many of the nurses mentioned that it was also the responsibility of a 'good nurse' in palliative care to pass on knowledge to other practitioners as affirmed in the following exemplars.

LIZ 18/H: *"If they are a good nurse - then they're willing to help people who they are working with who are perhaps not so expert. They should be willing to pass on their knowledge to them in order to try make the whole team a good team."*

SARAH 22/H: *"I think a good palliative nurse is somebody who liases well, who communicates and teaches. I think that's an extremely important role. You've got to pass on that knowledge because palliative care takes place everywhere, in the medical unit, in the surgical unit. You cannot be there all the time, I mean you're not there at one o'clock in the morning when someone is in pain".*

As indicated in the above exemplars, the majority of nurses maintained that it was the responsibility of a palliative care nurse to learn about palliative care and that without this knowledge and ongoing professional development they could not be a good palliative nurse. Many nurses indicated that 'learning about palliative care' involved education in the specific areas of pain and symptom control, communication skills, pharmacology and pathology. Being a good palliative care nurse also involved imparting their knowledge to other nurses, either by acting as a role model or by informal and formal teaching.

5.12.2 Professional experience

'Professional experience' was elicited as a theme cluster from actual nurse quotes and arose from the prompt "can you describe to me the sort of person that you feel is a good palliative care nurse?" Most of the nurse sample asserted that in order to become a 'good nurse' in palliative care s(he) already needed a background in general nursing and, therefore, professional experience. They believed that this gave them an insight into a variety of disease processes and medical problems, which provided them with a background to cope with dying patients more effectively. Interestingly, they did not believe a nurse could become a 'good nurse' by working only in palliative care. They argued that s(he) needed a background as a 'hands on nurse' in curative, as well as palliative, areas and that this equipped them with the much-needed tools of warmth, empathy and intuition- as well as self-awareness- to help them to cope with caring for dying patients. These arguments are presented in the exemplars below.

LINDA 4/B: "*If you've been around and seen a lot of things happening you've got a wider ranging knowledge and experience to fall back on. You can remember how you handled situations in the past. I'm fortunate in the sense that I feel I've had a reasonable background of experience working directly with patients. I think it's been invaluable - it counts for a lot.*"

JENNY 41/D: "*She (the good nurse) should already have a background in general nursing and other areas. She should have a number of years experience behind her....*"

The nurse sample believed that a good palliative care nurse did not have experience just in specialist palliative care. Indeed, they asserted that before working in the palliative care setting nurses needed a background in general nursing and to have had experience working in a variety of curative care settings.

5.12.3 Personal experience

'Personal experience' as a theme cluster was derived from actual nurse quotes and arose from the prompt "can you describe to me the sort of person that you feel is a

good palliative care nurse?" 'Personal experience' was viewed as a prerequisite for being a 'good nurse' in palliative care by a third of the nurses. These nurses had all had personal experience of caring for a dying relative. They argued that this experience gave them insight into patients' and carers' experiences and enabled them to be more empathetic to patients' needs and problems. The following two exemplars personify the views of several of the nurses interviewed.

ALISON 24/H: *"I think it helps if you have had personal experience yourself. I don't know if this is the right thing to say. I've had a lot of personal death myself and so I know the answers. I'm not saying I know all the answers for all people but I know the grieving process. I know it's different for everyone but I think I've got insight, insight into what it's like to lose someone that you love. So I can empathise with people and have some understanding into what people are going through. I have had to go through the pain so I understand other people's experience...."*

NICOLA 25/H: *"I think a lot of my own professional development is because I nursed my father who had cancer. He died at home. I think a lot of it is due to your life, what went on in your own life. You can empathise a bit more with people and I think that's what's happened to me over the last couple of years. I realised how I felt, how anxious I felt and it's made me look at things a wee bit differently."*

Nurses who had had personal experience of caring for a dying relative, or who had been bereaved, believed that this experience gave them greater insight into the needs of dying patients and relatives and enabled the nurse to develop empathy. This does not mean that the nurse who has not had personal experience of death does not also have empathy into the needs of dying patients or could not be a good palliative care nurse but that those who had experience were more likely to have insight into the needs of dying patients.

5.12.4 Summary

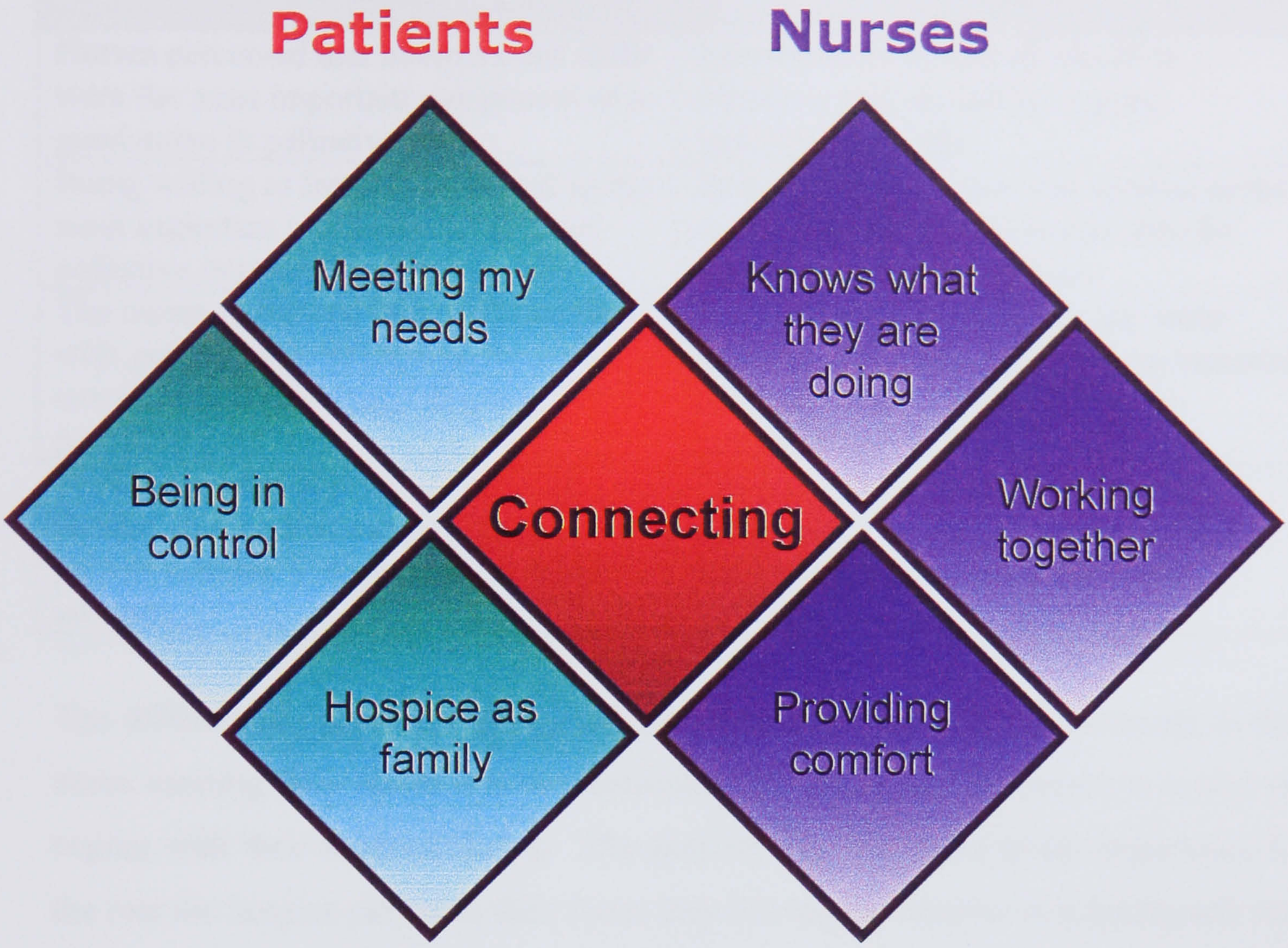
The theme category 'knows what they are doing' encapsulated a major aspect of how the nurses perceived their role in palliative care and how they described the good nurse in palliative care. The majority of nurses maintained that knowledge should

consist of learning about palliative care, particularly in the area of pain and symptom control. The importance of the nurse in having both professional and personal experience in nursing and palliative care was also expressed.

5.13 Overall summary

Figure 6 depicts the relationship between the nurse and patient theme categories. 'Connecting' is represented as the central theme category in red, as it was elicited from both nurse and patient data. Illustrating 'connecting' in the centre also indicates the fact that all the other theme categories co-exist with the nurse possessing good communication skills and the building and establishing of the nurse-patient relationship. Without good communication skills and an effective nurse patient-relationship, the other components of effective palliative care and characteristics of a good palliative care nurse could not occur. The theme clusters are not presented in the figure to avoid a clumsy and overloaded diagram. In terms of parallel themes other than 'connecting', 'meeting my needs' and 'providing comfort' have parallels in that both are related to the 'doing for' aspect of the nurse role.

Figure 6 Diagram of patient and nurse theme categories-in-depth interviews



The in-depth interview findings yielded interesting data. The findings demonstrated that there were both similarities (Table 16) and differences (Table 17) in terms of how the nurses and patients perceived effective palliative care and how they described the role of the nurse in palliative care. The similarities were that both groups perceived that interpersonal skills in palliative care were essential for good palliative nursing. Both patients and nurses believed that the way the nurse communicated with the patient was a vital component of providing effective palliative care. Both groups were of the opinion that talking about feelings was more important than superficial dialogue, and both groups discussed that establishing rapport and forming a trusting relationship between nurse and patient was essential. Both groups also outlined providing comfort as an important role of the nurse in palliative care. Both groups also believed that spending time with patients was an important component of the nurse's role.

Table 16 Similarities between nurses' and patients' in-depth interview data

NURSES	PATIENTS
Nurses perceived that interpersonal skills were the most important component of a good nurse in palliative care	Patients stressed that all nurses in palliative care should have good interpersonal skills
Being willing to listen was viewed as the most important interpersonal skill for palliative nurses by nurses	Being willing to listen was viewed as the most important interpersonal skill for palliative nurses by patients
The nurses perceived that spending time with patients was an important component of providing effective palliative care	The patients perceived that the nurse spending time with them was an essential component of providing effective palliative care
Providing comfort to the patient was viewed as a significant part of the palliative nurse's 'doing for' or 'hands on' role.	Providing comfort was seen by the patients as a key aspect of the nurse's role in terms of meeting my needs.

The differences (Table 17) comprised the importance the patients attributed to the nurse meeting their needs and the importance of remaining in control as a way of coping with their terminal illness. The patients also attributed much importance to the role the hospice played in their lives; they likened the hospice to a family and felt safe and secure there. The patients also attributed much importance to the nurse being there for them, particularly if they were feeling low or vulnerable.

The nurses, on the other hand, thought that multi-disciplinary care was an essential component of providing effective care. They felt that the nurse alone cannot provide optimum care for patients and their families. They attributed much importance to professionals working together in the best interest of patients. The nurses also attributed much importance to the nurse having both personal and professional knowledge and experience. They believed that the nurse could never become a good nurse in palliative care without the appropriate professional development.

The difference in amount of nurses and patient data is noted and is discussed in Chapter 6 section 6.1.

Table 17 Differences between nurses' and patients' in-depth interview data

NURSES	PATIENTS
The nurses perceived multi-disciplinary teamwork as an essential component of effective palliative care.	The patients perceived the importance of remaining in control as a way of coping with their terminal illness
The nurses perceived that knowledge of, and an ability to control, pain and distressing symptoms were essential for the good nurse in palliative care	The patients felt safe and secure in the hospice
Establishing a rapport and building a relationship were seen as essential aspects of palliative nursing care	The patients stressed the importance of the nurses being there for them, particularly if they were feeling low or vulnerable
The nurses indicated that knowledge and learning about palliative care, as well as personal and professional experience, were prerequisites for a good palliative nurse.	Spending time with patients was perceived as very important by the patients.
	The patients indicated that poor nursing care involved being avoided and isolated at distressing times, such as when the bad news of their diagnosis was given to them.
	An important component of good palliative nursing as far as the patients were concerned was the nurses' ability to get to know them as an individual.
	Patients expected nurses to be able to anticipate their problems intuitively, whether they were physical problems such as pain, or emotional problems such as getting upset.

Chapter 6 Repertory Grid Results

6.0 Introduction

This chapter presents the findings of the repertory grids from the 22 nurses and nine patients. The repertory grids were conducted on a different occasion from the in-depth interviews. The Discussion (chapter 7) brings together the in-depth interviews with the repertory grids. The presentation in this chapter includes both tables and graphs with an interpretation after each section. The nurse and patient findings are presented alongside each other with the nurses' findings first. This is different from the presentation in chapter 5 as there were unequal samples for the repertory grids (22 nurses and nine patients).

An explanation of the raw grid process and analysis can be found in chapter 4 and an example of a raw grid and a grid plotted by FLEXIGRID in the form of a cluster analysis can be found in Figure 2 and Appendix XI .

All the repertory grids were analysed firstly by FLEXIGRID as described in chapter 4. FLEXIGRID only performs analysis on grids separately. The nurses' and patients' grids were, therefore, compared using descriptive statistics (mean, median, standard deviation (SD) and standard error mean (SE) and inferential statistics (confidence interval; Mann-Whitney U test.). The statistical tests were performed using the MINITAB software package. The level of significance was set at $p<0.05$. The graphs were constructed using MICROSOFT EXCEL. Other abbreviations used include df = degrees of freedom and p = probability.

6.1 Landfield classification

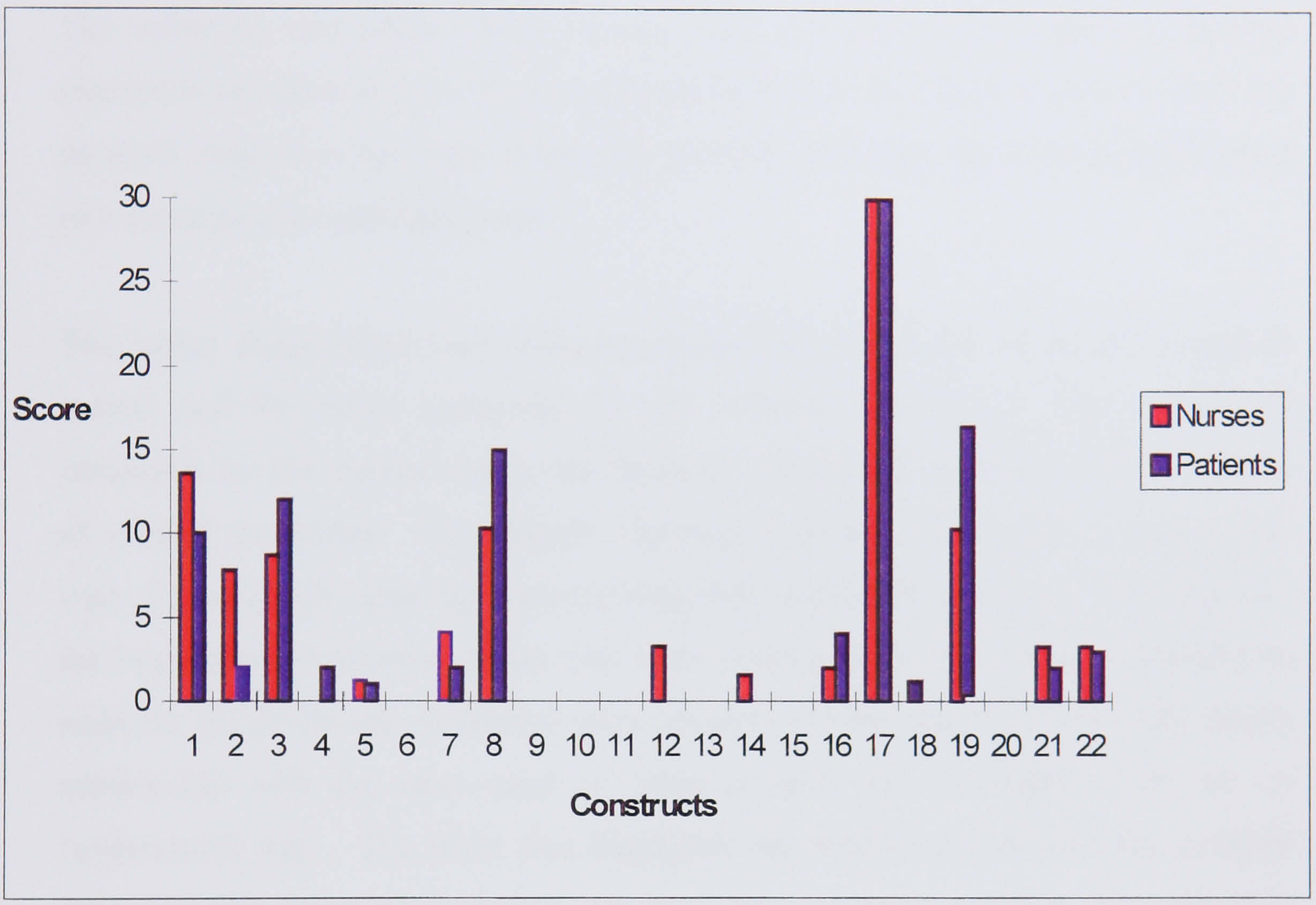
Table 18 presents the individual construct categories and the scores for the number of constructs falling within each category, for both nurses and patients, and these numbers expressed as a percentage of the total number of constructs elicited. There was a range of differences between the nurse and patient % scores. In several areas, status (5) tenderness (17) and humour (22), a high degree of commonality was expressed. It is also worth noting that a number of classifications were not used by either nurses or patients e.g. imagination, sexual, alternatives.

Table 18 Nurses and patients construct classification (Landfield (1971)

CONSTRUCT (N.B. POLE)	NURSES SCORE	PATIENTS SCORE
1. Social Interaction	33 (13.6%)	10 (10%)
2. Forcefulness	19 (7.8%)	2 (2%)
3. Organisation	21 (8.7%)	12 (12%)
4. Self Sufficiency	0	2 (2%)
5. Status	3 (1.2%)	1 (1%)
6. Factual Description	0	0
7. Intellective`	10 (4.1%)	2 (2%)
8. Self Reference	25 (10.3%)	15 (15%)
9. Imagination	0	0
10. Alternatives	0	0
11. Sexual	0	0
12. Morality	8 (3.3%)	0
13. External Appearance	0	0
14. Emotional Arousal	4 (1.6%)	0
15. Diffuse Generalisation	0	0
16. Egoism	5 (2%)	4 (4%)
17. Tenderness	70 (30%)	30 (30%)
18. Time Orientation	3 (1.2%)	0
19. Involvement	25 (10.3%)	16 (16%)
20. Comparatives	0	0
21. External qualifiers	8 (3.3%)	2 (2%)
22. Humour	8 (3.3%)	3 (3%)
Total	**242**	**99**

The graph (Figure 7) presents the content analysis of all the elicited constructs for both nurses (n=22) and patients (n=9) using the Landfield (1971) system for construct classification. A full explanation of each Landfield category can be found in Appendix X. The similarity between the nurse and patient data can be noted.

Figure 7 Graph of Landfield construct classification score by constructs



The majority of constructs for both groups fell into the categories of tenderness, social interaction, involvement and self-reference. These characteristics are associated with caring. Many nurses and patients used terms such as '*kind, compassionate and warm*' to describe aspects of caring rather than knowledge, experience, skill or moral terms. The characteristics of good caring as agreed by nurses and patients were- someone who is committed, considerate, concerned for others, compassionate, warm, kind, understanding, and is close to them. 'Bad caring' was the opposite. Thus it would appear that nurses and patients perceived what constituted 'good and bad caring' in similar ways. These characteristics are also comparable with the in-depth interview data (see Figure 6). The patients and nurses referred to good nurses as being caring, effective listeners, compassionate and empathetic. Bad nurses were

empathetic. Bad nurses were referred to as being people who did nor listen to them or who ignored them, as well as people who did not spend time with them and who were nor committed to their job. The results, therefore, indicate the importance that both patients and nurses attributed to interpersonal skills as well as the nurses spending time with patients and demonstrating a commitment to care.

6.2 Ranking of elicited constructs

The following two tables (Table 19 and Table 20) contain the ranking of elicited constructs and their classification using Landfield, and the theme categories from the in-depth interviews for both nurses and patients indicating the most highly ranked two constructs for each informant.

The tables demonstrate how these constructs were classified using the Landfield system and the theme categories for the in-depth interviews. The majority of constructs for the nurses were in the category 'tenderness' as in the classification of all elicited constructs. The patients' top rated constructs were more evenly spread over six categories, with the majority classified under self-reference. This indicates the importance attached to carers who were close to them or to family members. In addition, 20 of the 62 constructs were concerned with aspects of the individual's relationship with the carer, such as 'close to me', 'has an affinity with me' or 'understands me'. The table also highlights the interaction between the in-depth interview and repertory grid data and how the two methodologies complemented each other. For instance, 'interested in me - only interested in self' (Table 20) has a direct correlation in the patients' theme categories- the theme cluster 'getting to know me'. As these constructs were all elicited constructs and, therefore, individual to the informants, no statistical analysis could be performed to ascertain differences between the patient and nurse groups.

Table 19- Mean scores- constructs which scored high on percentage of total variance and therefore important constructs to the individuals - nurses- (elicited constructs only)

SUBJECT	CONSTRUCT	LANDFIELD CLASSIFICATION	THEME CATEGORY CLASSIFICATION	% OF TOT. VAR.
1. Jack	scatter brained- thorough lacks awareness- tuned in	Organisation Social Interaction	- Connecting	8.32 7.73
2. Amanda	stand offish - friendly feel close to them- feel detached- not close to them	Social interaction Self reference	- -	9.64 8.87
3. Linda	difficult to approach- has affinity with me close to me- estranged	Social interaction Self reference	- -	9.88 9.01
4. Beth	strong family bond- weak bond not interested in me as a person- interested in me	Self reference Tenderness	- Building rapport	17.98 12.57
5. Mary	appearances matter - sees beyond outer cover comes when I want them- lack of commitment	Social interaction Involvement	Connecting Providing comfort	11.23 10.32
6. Sandra	doesn't understand me- has insight into who I am only knows about illness- concern about peace of mind	Tenderness Intellective	Building rapport Providing comfort	12.89 11.08
7. Toni	similar temperament to me- opposite to me enduring relationship to me- acquaintance	Self reference Self reference	- -	13.96 11.30
8. Lisa	able to show they care- unable to show emotion tactful- tactless	Tenderness Social Interaction	Providing comfort -	10.76 10.49
9. Liz	shallow- deep narrow mined- broad minded	Social interaction Forcefulness	- -	11.61 9.41
10. Rachel	considerate- inconsiderate understands me - doesn't understand me	Tenderness Tenderness	Providing comfort Building rapport	9.54 8.15
11. Teresa	cold- warm loving- disinterested	Tenderness Tenderness	Providing comfort -	9.55 9.26
12. Sarah	pessimistic- optimistic sense of humour- serious	Time orientation Humour	- Building rapport	10.78 8.85
13. Alison	loves me - doesn't love me realistic- not realistic	Self reference Organisation	- -	12.19 11.99
14. Nicola	up to date re symptoms- not up to date thoughtful - brash	Intellective Tenderness	Knows what doing Building Rapport	8.05 8.02
15. Jason	hides emotion - open with emotion good listener- distracted person	Emotional arousal Social interaction	- Connecting	9.34 8.46

16. Kath	fusses too much- wouldn't fuss no emotional involvement- too much involvement	Organisation Involvement	- -	16.76 10.90
17. Samantha	have no confidence in them- have confidence in them don't like them -like them	Social interaction Self reference	Building rapport -	8.97 8.59
18. Gillian	very like me- would understand me close to me- don't get on with them	Self reference Self reference	- Building rapport	10.55 10.26
19. Christine	sure of self- too sure of self would keep confidences- would talk to every body	Egoism Social interaction	- Building rapport	11.57 10.48
20. Emma	consistently caring people- brusque considerate- inconsiderate	Tenderness Tenderness	Providing comfort Providing comfort	12.39 12.23
21. Fiona	obnoxious- genuine obsessive- balanced	Forcefulness External qualifier	- -	10.73 10.67
22. Jenny	has medical knowledge- lacks knowledge skilled in their job - unskilled	Intellective Involvement	Knows what doing Knows what doing	18.08 13.62

Table 20 Mean scores of constructs which scored high on percentage of total variance and therefore important constructs to the individuals - patients (elicited constructs only)

SUBJECT	CONSTRUCT	LANDFIELD CLASSIFICATION	THEME CATEGORY CLASSIFICATION	% OF TOTAL VARIANCE
1. Bill	kindness- selfish naive- worldly	Tenderness Intellective	- -	17.57 11.03
2. Josie	immature-mature unfit to look after me- fit to look after me	Self-sufficiency Involvement	Meeting my needs Meeting my needs -	8.61 8.30
3. Jerry	bad listener- could talk in confidence troublemaker- treats people as find them	Social interaction Social interaction	Connecting -	9.24 8.64
4. Alan	very dependable- not dependable I get on well with them- don't get on well with them	External qualifier Self reference	- -	8.57 8.57
5. Tim	interested in me- only interested in self not very nice person- do like them	Tenderness Self Reference	Connecting -	8.58 7.97
6. Anne	unhelpful- helpful showed dedication- did not show dedication	Tenderness Involvement	Meeting my needs Meeting my needs	10.81 9.65
7. Emily	knows me- doesn't know me terrible person- wonderful person	Self reference External qualifier	Connecting -	8.29 8.14
8. Selina	realistic-optimistic dramatic- undramatic	Self-sufficiency Forcefulness	- -	12.20 11.97
9. Brian	related to me -not related to me experienced - no experience	Self reference Intellective	- Meeting my needs	12.76 8.05

6.3 Principal component analysis - percentage of total variance

Figure 8 and Table 21 present the percentage of total variance accounted for by the first principal component for both nurses and patients. The higher the percentage of total variance accounted for by the first principal components, the more tightly organised and unidimensional was the individual's construing.

Figure 8 Graph of percentage of total variance, variance score by number of informants

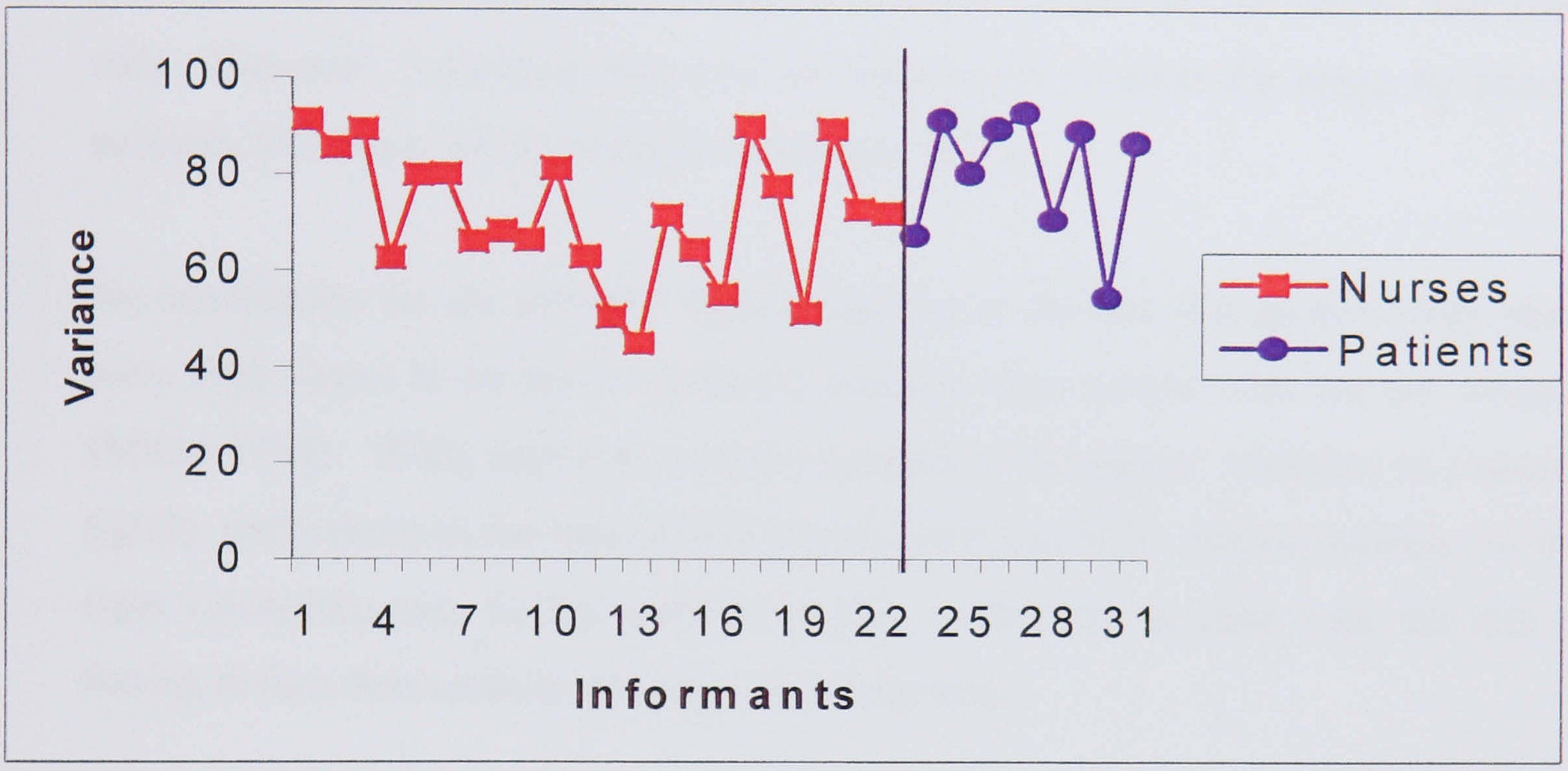


Table 21 Statistical results for the percentage of total variance - comparing patient and nurse data

	NURSES	PATIENTS	OVERALL TESTS
Mean	71.2	80.0	
Median	71.3	86.3	
Standard Deviation	13.7	13.2	
Standard Error Mean	2.9	4.4	
Confidence Interval			95% CI (-20.1, 2.5)
Mann -Whitney U test			p= 0.09.

The findings demonstrate that both the nurses and patients had a tendency to construe tightly. 'Tight construing' involves the person seeing their world in black-white or

uni-dimensional terms (Winter 1992). Tightness of constructions may be employed as a defensive strategy to counter anxiety. The person who construes tightly builds a system which is designed to be 'anxiety tight' (Kelly 1955). The implications for tight construing will be discussed in more detail in chapter 7. The nurses' scores ranged from 44.8-90.9, and the patients' range was from 54.2-92.5. The patients' mean and median of the percentage of total variance are higher overall but not statistically significant (Mann-Whitney U test p=0.09). The standard deviation and standard error results reflect the diversity in ranges of scores for both nurses and patients. The graph also demonstrates the similarity between the patient and nurse data. However, both these data sets are significantly outside the range for normal subjects (39.4 in a 16x16 grid Ryle and Breen 1972).

An explanation for the patients' tight construing is the fact that people under stress have been found to be less cognitively complex than people who are not stressed (Miller 1968). What, however, is more unusual is the nurses' tendency to construe tightly, particularly in the case of Jack whose score was 90.9. An explanation for this tight construing may be the mechanism that nurses use to cope with the fact of having to face death and dying issues on a daily basis.

Another explanation for the high percentage of variance scores is that a relatively small grid was used which contained a restricted range of convenience, that is the grid was limited to perceptions of carers.

6.4 Percentage of variance accounted for by the supplied constructs

Findings for the three supplied constructs 'caring- not caring', 'someone I can talk to - someone I can't talk to' and 'someone I trust - someone I don't trust' are presented in the next section. Only the percentage of total variance column was compared, as this score had more meaning in terms of comparison than the mean and standard deviation scores.

6.4.1 Caring= (7) not caring= (1)

Nurses and patients were asked to rate the construct caring-uncaring against their elements (carers) on a scale of 7-1, with 7 being the best score for caring and 1 being the worst score for uncaring. Figure 9 and Table 22 present the results of the percentage of variance accounted for by the construct.

Figure 9 Graph of nurses' and patients' percentage of total variance scores for the construct caring-uncaring

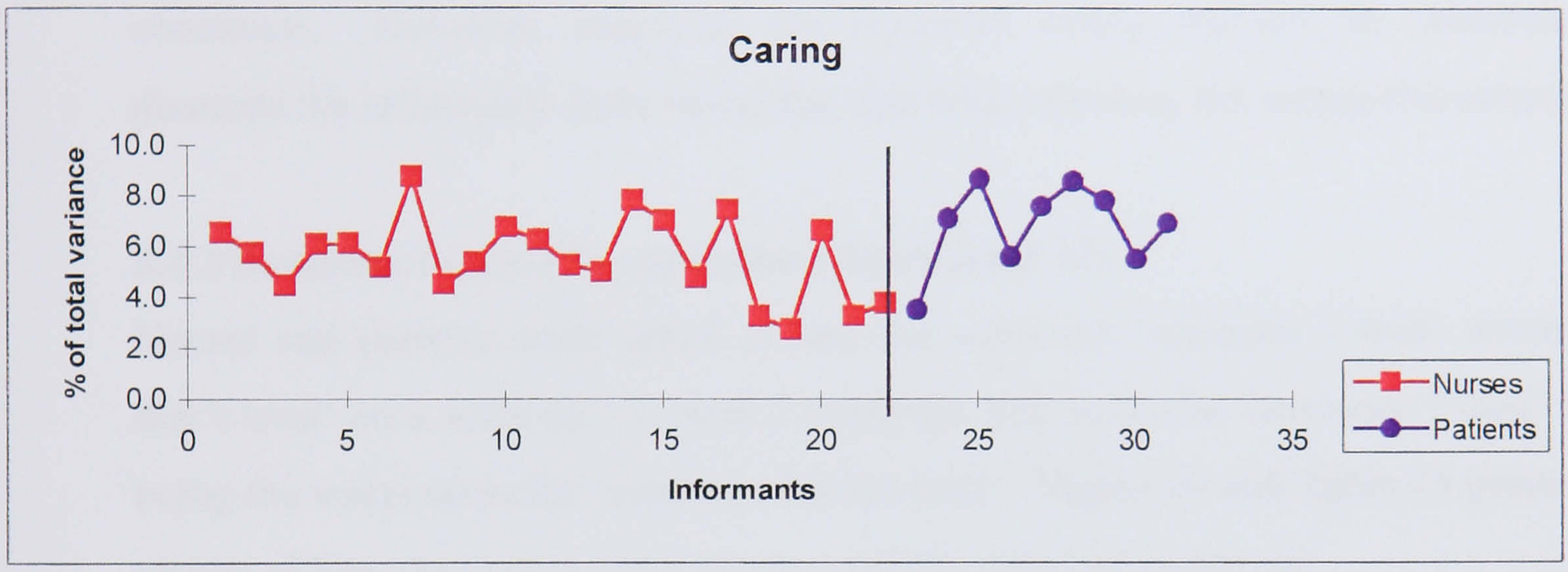


Table 22- Statistical results for nurses' and patients' rating of total variance scores for the construct caring-uncaring

	Nurses	Patients	Overall Tests
Mean of % Total Variance	5.5	6.8	
Median of % Total Variance	5.5	7.1	
Standard Deviation	1.6	1.7	
Standard Error Mean	0.3	0.6	
Confidence Interval			95% CI (-2.6, 0.15)
Mann -Whitney U test			p = 0.05.

The nurses' scores ranged form 2.7-8.7 and the patients' scores ranged from 3.5- 8.6. for the construct 'caring-not caring'. There was no statistical difference between the two groups (Mann-Whitney p=0.05). In neither sample did the construct 'caring'

appear to be particularly 'superordinate' in terms of accounting for a high percentage of variance in the grid (section 3.21). A high score for a superordinate construct was for the construct, 'kindness-selfishness' (17.57) in Bill's grid (2/A) or the construct, 'fusses too much-wouldn't fuss' (16.76) in Kath's grid (28/H). The high scores indicate the significance of the construct for the individual. In other words, Bill perceived that 'kindness' was a more important characteristic of caring than 'caring'. A reason for this may be that as informants were asked to describe constructs of caring in their elicited constructs when they came to rate elements on 'caring-not caring', they perceived that they had already done this with their previous elicited constructs. However, supplying the construct caring enabled the researcher to dissuade the informants from using that title when eliciting the caring characteristics.

6.4.2 Someone I trust (7) - someone I don't trust (1)

Nurses and patients were asked to rate the construct 'someone I trust- someone I don't trust' on a scale of 7-1, with 7 being the best score for 'someone I trust' and 1 being the worst score for 'someone I don't trust'. Figure 10 and Table 23 present the results of how the nurses and patients rated the supplied construct.

Figure 10 Graph of nurses' and patients' for the percentage of total variance scores of the construct someone I trust- someone I don't trust

Table 23 Statistical results nurses' and patients' percentage of total variance scores for the construct 'someone I trust - someone I don't trust'

	NURSES	PATIENTS	OVERALL TESTS
Mean of % Total Variance	6.4	6.5	
Median of % Total Variance	6.2	6.9	
Standard Deviation	2.4	1.1	
Standard Error Mean	0.5	0.4	
Confidence Interval			95% CI (-1.4, 1.2)
Mann -Whitney U test			p= 0.9

The nurses' scores for the supplied construct 'someone I trust' (Figure 10) ranged from 3.1-11.0 and the patients' scores from 5.0-8.3. There was a broader range in the nurses' findings, with nine nurses scoring the construct over 7.1, indicating the importance they attributed to the concept of trust, but no significant differences (p=0.9; 95% CI).

6.4.3 Someone I can talk to (7)- someone I can't talk to (1)

Nurses and patients were asked to rate the construct 'someone I can talk to - someone I can't talk to' on a scale of 7-1, with 7 being the best score for 'someone I can talk to'' and 1 being the worst score for ''someone I can't talk to'. Figure 11 and Table 24 present the results of how the nurses and patients rated the construct.

Figure 11 Graph of nurses' and patients' percentage of total variance scores for the construct someone I can talk to-someone I can't talk to

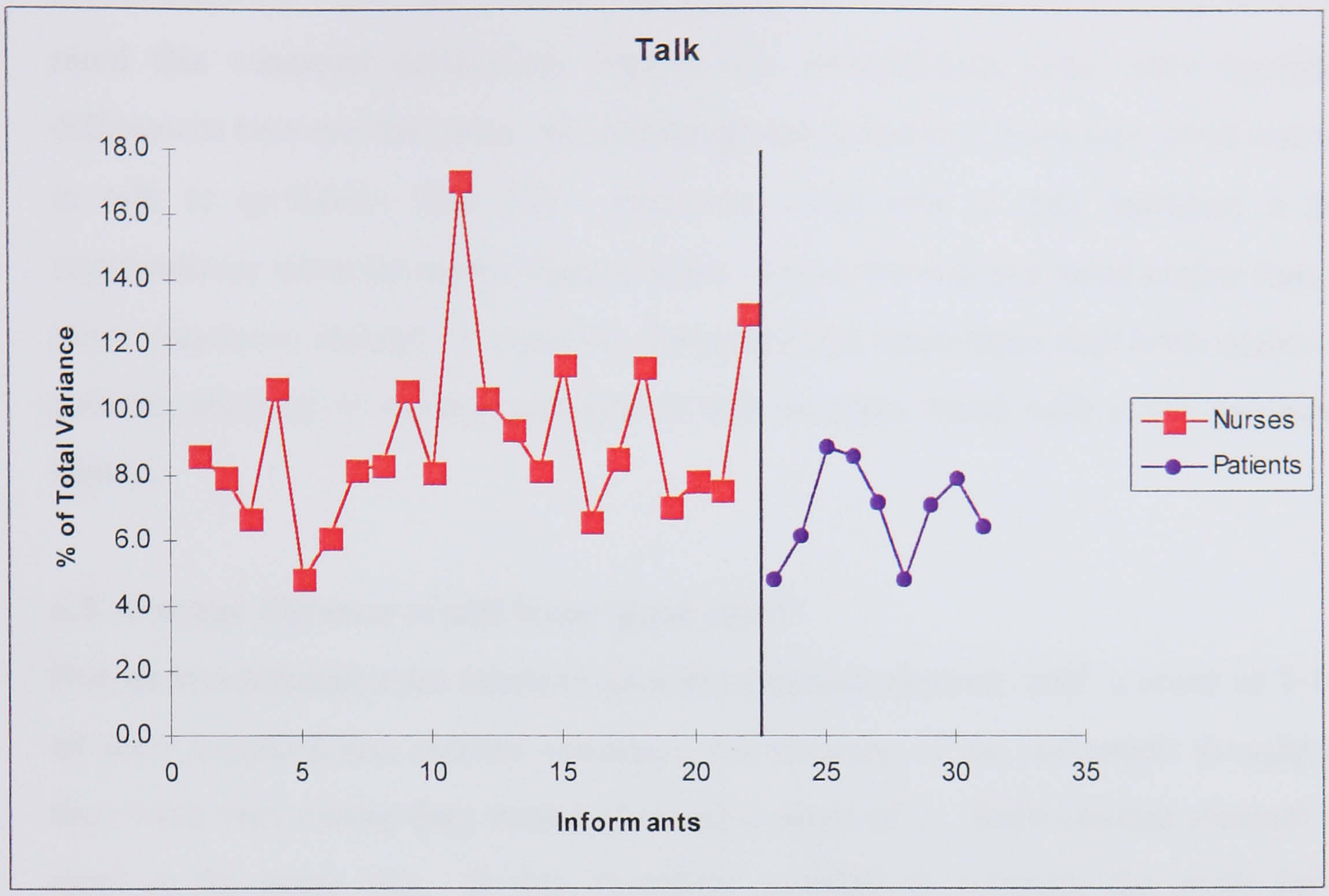


Table 24 Statistical results for nurses' and patients' percentage of total variance scores for the construct 'someone I can talk to – someone I can't talk to'

	NURSES	PATIENTS	OVERALL TESTS
Mean of % Total Variance	9.0	6.9	
Median of % Total Variance	8.2	7.1	
Standard Deviation	2.6	1.5	
Standard Error Mean	0.6	0.5	
Confidence Interval			95% CI (0.6, 3.7)
Mann -Whitney U test			p = 0.03.

The supplied construct 'someone I can talk to' was analysed in the same way as the other supplied constructs. The nurses' scores ranged from 4.8 - 17.0 and the patients' scores from 4.1 - 8.9. As evident from Figure 11, there was one outlying nurse who rated this construct particularly highly, but, nevertheless, there were significant differences between the nurse and patient groups in terms of how they rated someone to talk to ($p<0.001$; 95% CI). Someone I can talk to was therefore a more superordinate issue for nurses than patients. This construct was rated higher than any other construct, elicited or supplied, indicating the importance that both nurses and patients attribute to having someone to talk to when faced with a life threatening illness.

6.5 Average distance of self from 'good carer'

Nurses and patients were asked to give the supplied element 'self' a score of 7-1 for all their supplied and elicited construct; for instance, if the informant thought that they were very caring they would give *self* a score of 7. Each elicited element was rated in the same way. It was, therefore, possible to compare the score for the informants' good carer (the carer that they rated the most highly within their grid) with their *self*. Figure 12 and Table 25 present the results from measuring the average distance between the informants' *self* from their good carer.

'Eyeballing' the grids revealed that 78% of the patients and 41% of nurses identified their 'good carer' as a member of their family. In addition, 32% of the nurses identified a close friend as their 'good carer'. Therefore, only 22% of patients and 27 % of nurses identified a nurse as their 'good carer'. On the other hand, 67% of patients and 86% of nurses indicated that their 'bad carer' was a nurse or doctor.

Perhaps it is not surprising that the nurses, thinking of a time when they might be seriously ill, revealed that they would prefer to have a family member or close friend caring for them. It is more surprising that the majority of patients chose a family member as their 'good carer', particularly when they were all facing the issue of 'feeling a burden' to their family.

Figure 12 Graph of nurses' and patients perception of self in relation to 'good carer'

Table 25 Statistical results for distance between 'self' and the informant's good carer.

	NURSES	PATIENTS	OVERALL TESTS
Mean	0.5	0.6	
Median	0.5	0.4	
Standard Deviation	0.3	0.2	
Standard Error Mean	0.1	0.0	
Confidence Interval			95% CI (-0.118, 0.39)
Mann -Whitney U test			p =0.15

The results reveal how the informants perceived themselves in terms of caring. There were no significant differences between how nurses and patients rated themselves with their 'good carer'. A value of 0 indicated that the informant perceived themselves as the same as their 'good carer'. The nurses rated themselves from 0.2-1.0 in

from 0.2-1.0 in comparison to their good carer. The patients rated themselves from 0.0-1.1 with their 'good carer'. No nurses, and only one patient, rated themselves as the same as their 'good carer'.

6.5.1 Average distance of ideal self from 'good carer'

Nurses and patients were asked to give the supplied element *ideal self* a score of 7-1 for all their supplied and elicited constructs, for instance, if the informant thought that they were would like to be very caring they would give *ideal self* a score of 7. Figure 13 and Table 26 present the results from measuring the average distance between the informants' *ideal self* from their 'good carer'

Figure 13 Graph of nurses' and patients perception of ideal self in relation to 'good carer'

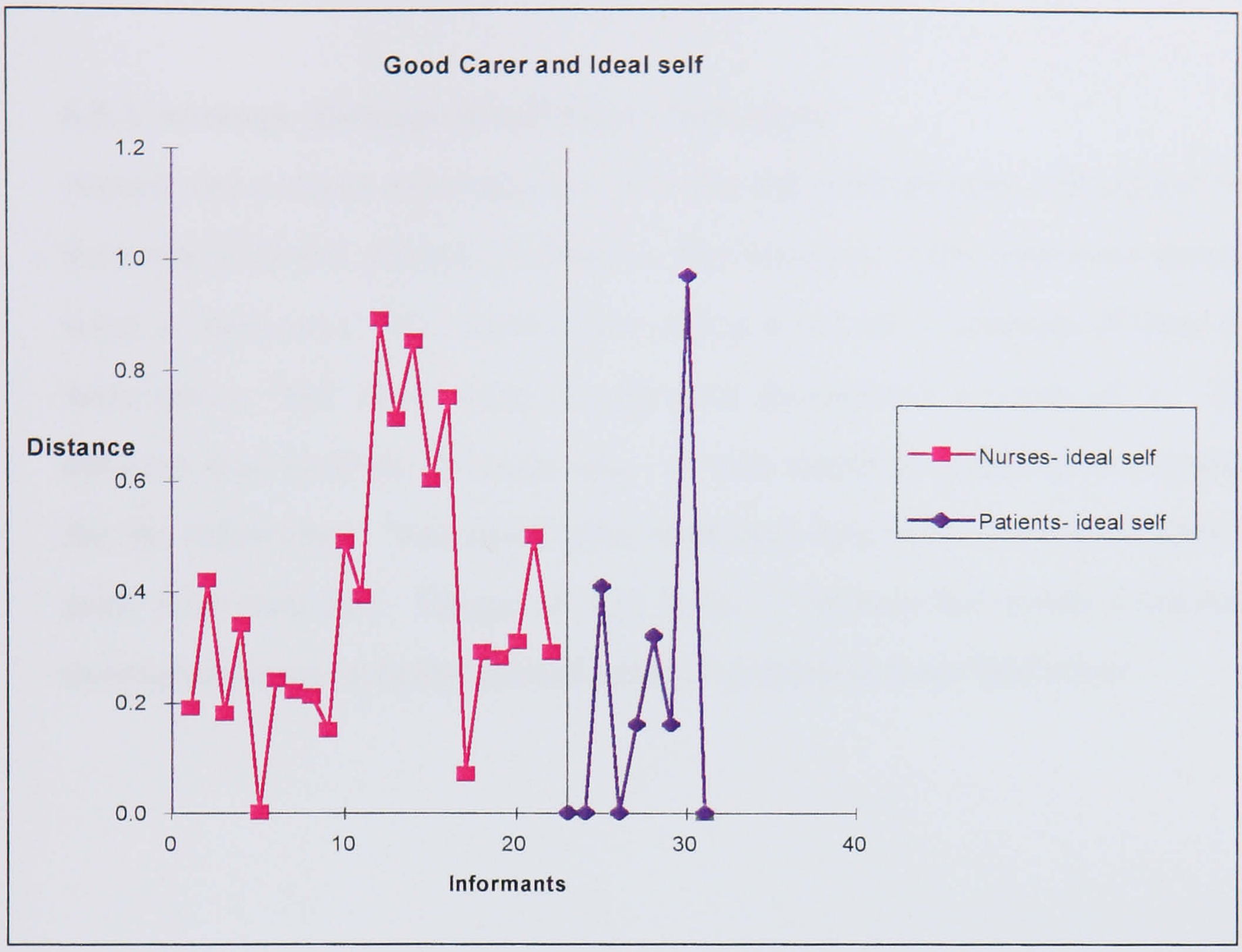


Table 26 Statistical results for distance between 'ideal self' and the informant's good carer.

	NURSES	PATIENTS	OVERALL TESTS
Mean	0.5	0.6	
Median	0.5	0.4	
Standard Deviation	0.3	0.2	
Standard Error Mean	0.1	0.0	
Confidence Interval			95% CI (-0.118, 0.39)
Mann -Whitney U test			p =0.15

The results reveal how the informants perceived their *ideal self* in terms of caring. There were no significant differences between how nurses and patients rated their *ideal self* with their 'good carer'. A value of 0 indicated that the informant perceived their *ideal self* the same as their 'good carer'. The nurses rated their *ideal self* 0.0-

in comparison to their 'good carer'. The patients rated their ideal self from 0.0-1.0 with their 'good carer'. Interestingly, only one nurse and two patients rated their 'ideal self' the same as their 'good carer'

6.5.2 Average distance of self from 'bad carer'

Nurses and patients were asked to give the supplied element *self* a score of 7-1 for all their supplied and elicited constructs. For instance, if the informant thought that they were a 'bad carer' they would give *self* a score of 7, whereas if they thought they were not a 'bad carer' they would give themselves a score of 1. Each elicited element was rated in the same way. It was therefore possible to compare the score for the informants' 'bad carer' (the carer that they rated the least highly within their grid) with their self. Figure 14 and Table 27 present the results from measuring the average distance between the informants' *self* from their 'bad carer'.

Figure 14 Nurses' and patients perception of self in relation to 'bad carer'

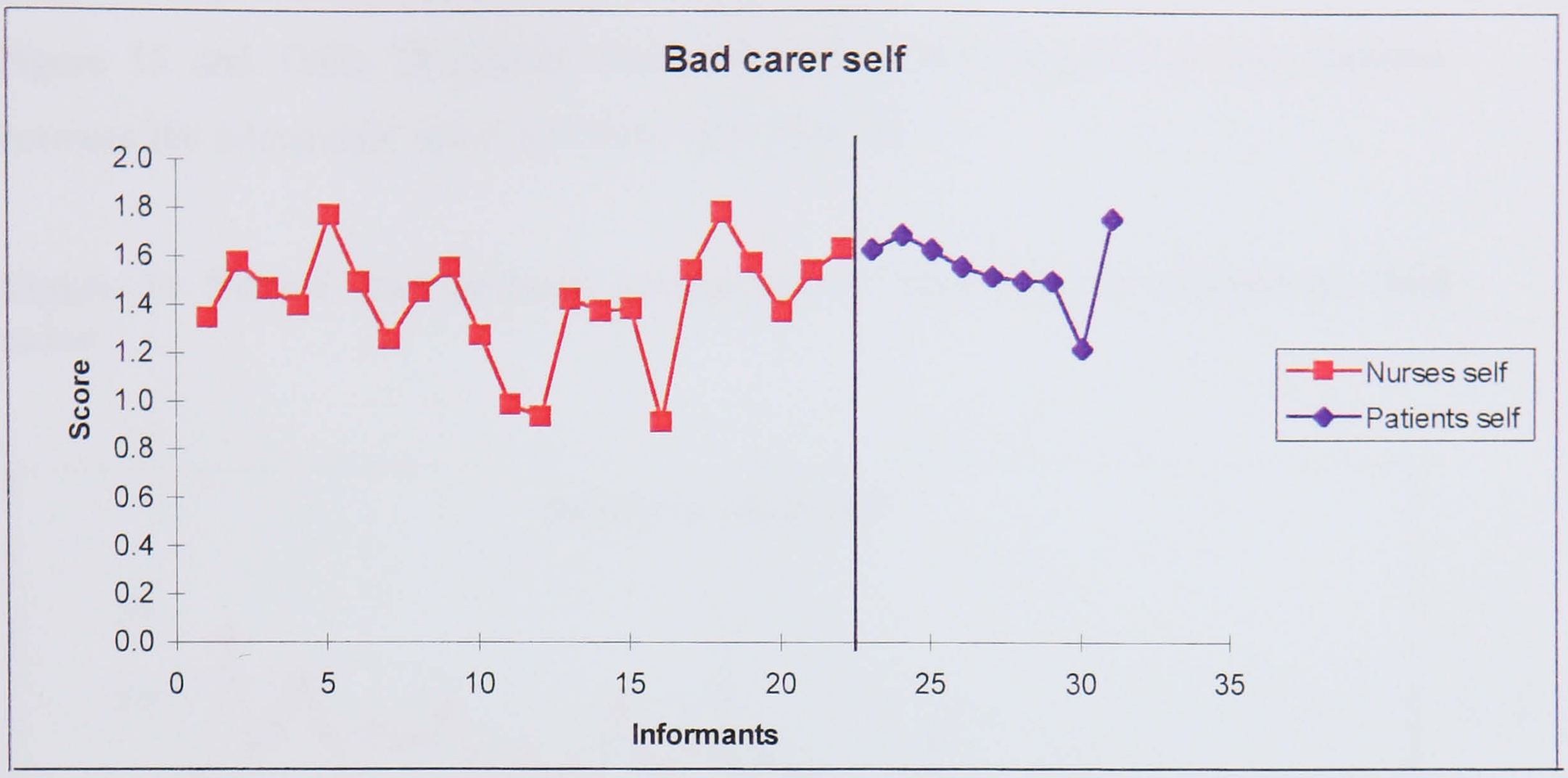


Table 27- Statistical results for distance between 'self' and the informant's bad carer.

	NURSES	PATIENTS	OVERALL TESTS
Mean	1.4	0.3	
Median	1.4	0.3	
Standard Deviation	0.2	0.3	
Standard Error Mean	0.0	0.1	
Confidence Interval			95% CI (-0.3 0,009)
Mann -Whitney U test			p= 0.07

The results indicate that both the nurses and patient groups identified that they were not like their perceived 'bad carers'. The lack of variation between results demonstrates that no nurse or patient felt that they were like their 'bad carer'. They did not therefore want to have the characteristics they had attributed to their 'bad carers'. Nurses saw themselves as particularly far removed from their perceived 'bad carers', but, while this may be important, it was not statistically significant. The difference between nurses and patients regarding 'self and bad carers' was weakly significant (p=0.05; 95%CI). These results, are however, not surprising. What could have been more surprising was if experienced palliative care nurses perceived that they *were* bad carers.

6.5.3 Average distance of ideal self from 'bad carer'

Figure 15 and Table 28 present the results from measuring the average distance between the informants' *ideal self* from their 'bad carer'.

Figure 15 Nurses' and patients perception of 'ideal self' in relation to 'bad carer'

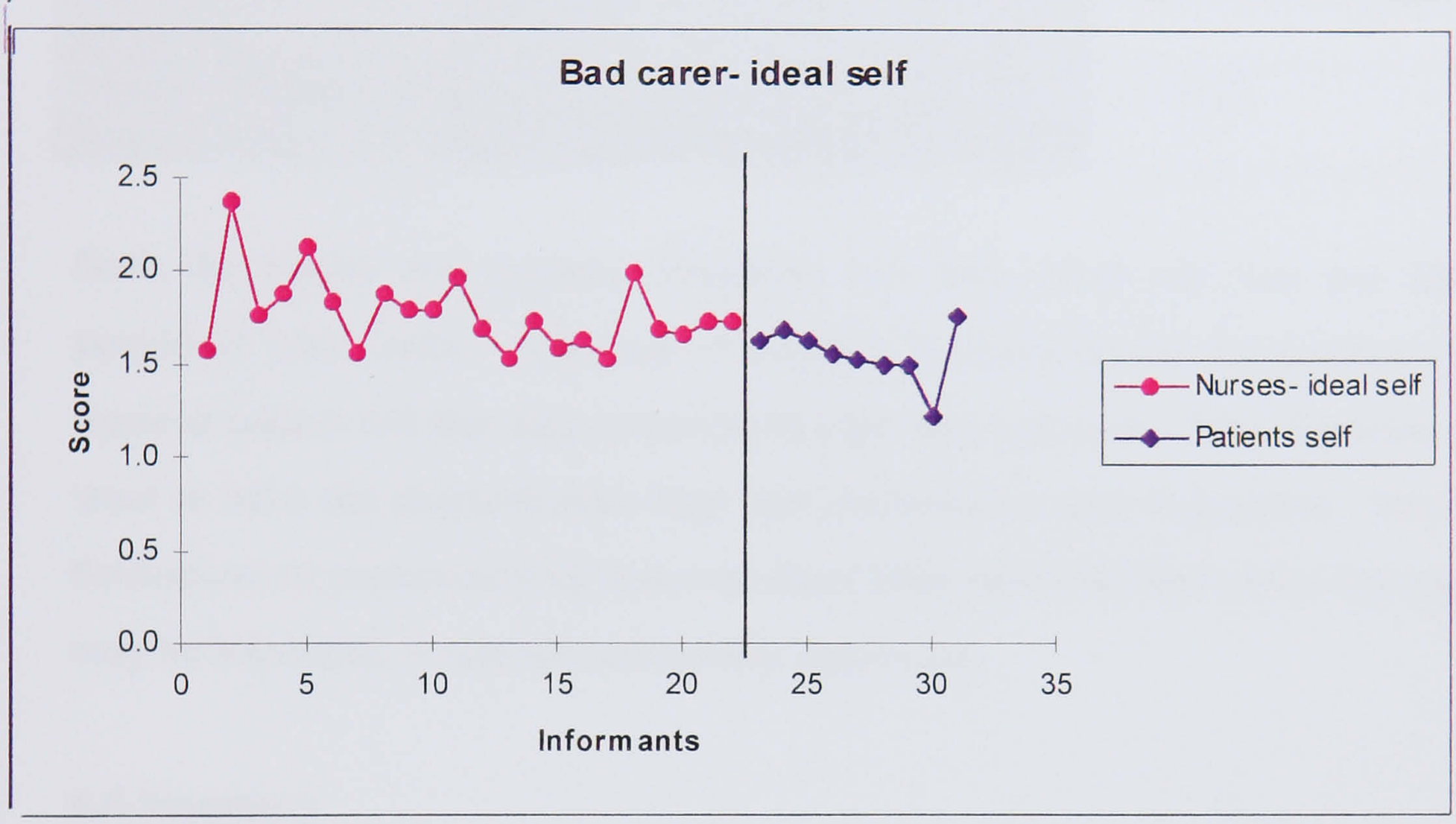


Table 28 Statistical results for distance between 'ideal self' and the informant's 'bad carer'.

	NURSES	PATIENTS	OVERALL TESTS
Mean	1.8	1.6	
Median	1.7	1.7	
Standard Deviation	0.2	0.2	
Standard Error Mean	0.04	0.06	
Confidence Interval			95% CI (-0.3 0,009)
Mann -Whitney U test			p= 0.07

Both the nurses and patients identified that their *ideal self* was not like their perceived 'bad carers'. The lack of variation between results demonstrates that no nurse or patient felt that they wanted to be like their bad carer. They therefore did not want to have the characteristics they had attributed to their bad carers. Nurses saw themselves as particularly far removed from their perceived bad carers but while this may be important, it was not statistically significant.

6.6 Summary

To conclude: overall there were few differences between how the nurses and patients perceived characteristics of caring. Patients viewed caring characteristics as good listener, helpful, realistic, dependable, dedicated, kind, experienced, interested in me, can talk in confidence, knows me. Nurses viewed caring characteristics as shows they care, tuned in, broadminded, interested in me, understands me, knowledgeable, close to me, committed, considerate, thorough, sense of fun, loving, realistic, genuine, warm, friendly, concerned and deep. Patients perceived uncaring characteristics to be bad listener, not experienced, selfish, unfit to look after me, avoids me, does not help me, selfish and immature.

The nurses perceived uncaring characteristics to be obsessive, too sure of self, unskilled, obnoxious, brusque, no confidence in person, fusses too much, hides emotion, lacks awareness, unfriendly, unapproachable, lacks commitment, shallow person, cold person, pessimistic, unrealistic, not up to date, lacks knowledge. The

key issues to emerge from the repertory grid findings were the majority of patients and nurses perceived positive and negative characteristics of caring in terms of issues of interpersonal communication, tenderness and commitment to their work. Both nurses and patients perceived good carers as people close to them, with the majority of informants rating family highly in terms of positive caring characteristics. Both groups had a tendency to construe tightly. This was more understandable in the patient group than the nurse group, and therefore, has implications for recruitment and supervision of nurses in palliative care (see chapter 7). From the supplied constructs, 'someone I can talk to' was most superordinate in the nurse group. This indicates the importance nurses attribute to effective communication in palliative care. Finally, both groups wanted to have similar characteristics to their good carers and did not want to be like their bad carers.

6.7 Triangulation of findings

The following section triangulates the key findings from both the in-depth interviews and repertory grids. A discussion of these findings is presented in chapter 7.

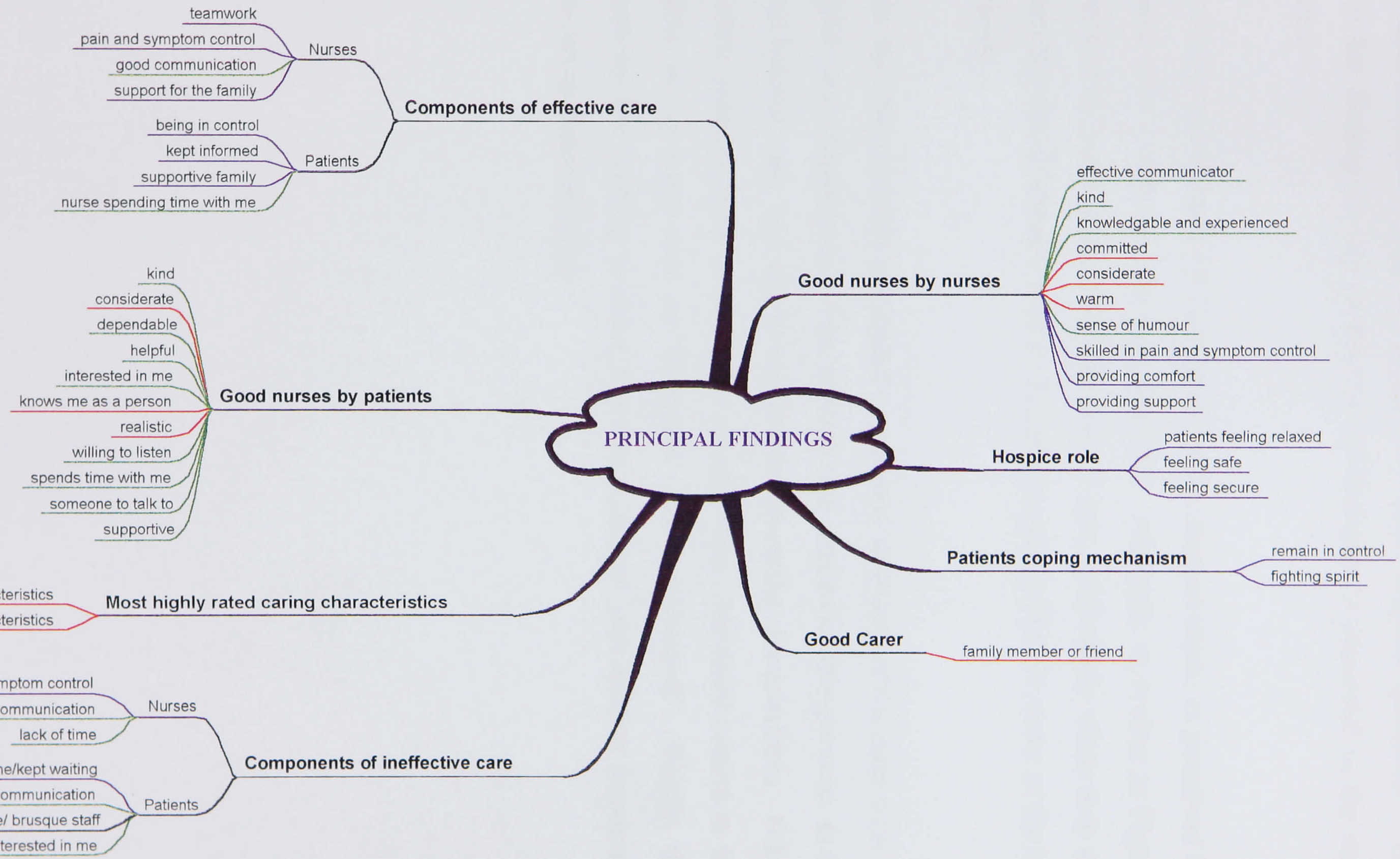
6.7.1 Principal findings

Figure 16 presents the principal findings of the study diagrammatically. The findings unique to the in-depth interviews are coloured blue. The findings unique to the repertory grids are coloured red and the findings common to both sets of data are coloured green.

The principal findings incorporate the patients' and nurses' perceptions of a good palliative care nurse and their views of effective and ineffective palliative care. Key findings are presented, namely the most highly rated caring characteristics, the role the hospice played in patient's lives, how patients coped with their terminal illness and who they perceived to be a 'good carer'.

Figure 16 demonstrates, therefore, that although some findings are unique to the in-depth interviews, reflecting the nature of the tool- namely patients' coping mechanism and hospice role, which are related to the lived experience of the informants. Moreover some findings, for the same reasons are specific to the repertory grids- namely highly rated characteristics, family and friend as good carers and some of the descriptors related to caring characteristics. There are, however, a significant number of the findings that are common to both sets of data- such as: many of the components of effective and ineffective care, and the attributes and characteristics of a good palliative nurse. This demonstrates both the importance of those specific findings and the ability of the tools to add rigour to each others set of findings.

Figure 16 Diagram Representing Principal Findings



6.7.2 Characteristics of caring

The triangulation of the findings in relation to the characteristics of caring are presented diagrammatically, with a rationale of each diagram proffered. The discussion of the findings in the context of the literature is presented in the next chapter (section 7. 2)

Figure 17 indicates conceptually the key good caring characteristics, as perceived by patients, drawn mainly from the repertory grid data. Although, as evident in Figure 16 some characteristics are present in both sets of data, particularly when they are characteristics that the informants used to describe a good palliative nurse in the in-depth interviews.

On the whole, the characteristics are related to personal attributes of the carer such as 'kind', 'helpful' and 'dependable'. The patients also perceived interpersonal skills such as 'good listener' and 'can talk in confidence' as caring characteristics. Other important caring characteristics as far as the patients were concerned related to the professionalism of the nurse such as 'dedicated' and 'experienced'. Finally, the patients perceived that 'getting to know them as a person' was another important dimension to caring characteristics.

Figure 17 Diagram representing patients' perceptions of good caring characteristics

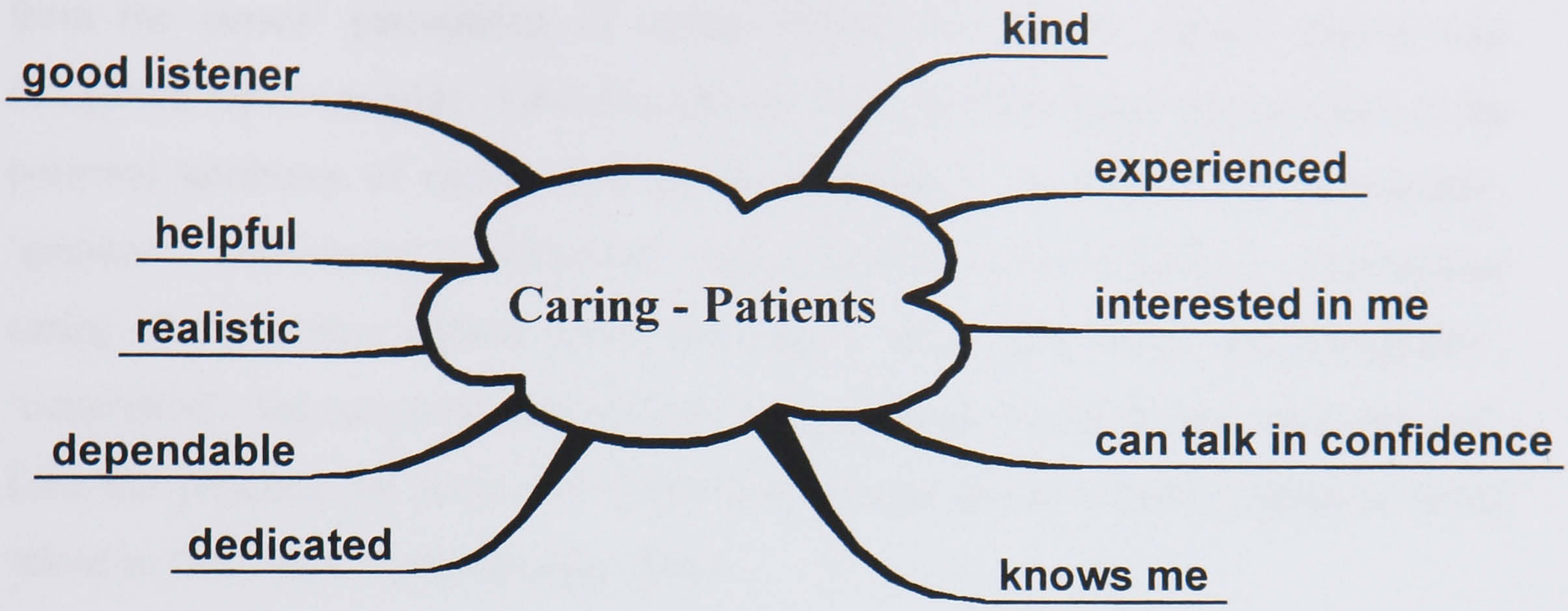


Figure 18, on the other hand, depicts those characteristics that the patient sample stated were uncaring. The characteristics tended to be the opposite to the caring characteristics (as indicative of repertory grids, where bipolar opposites are elicited). For instance, bad or uncaring activities in relation to interpersonal skills were 'bad listener', 'avoids me'. Other uncaring characteristics were related to the lack of professionalism of carers such as 'not experienced', 'does not help me'. Other characteristics related to personal attributes of carers such as 'immature' and 'selfish'.

Figure 18 Diagram representing patients' perceptions of uncaring characteristics

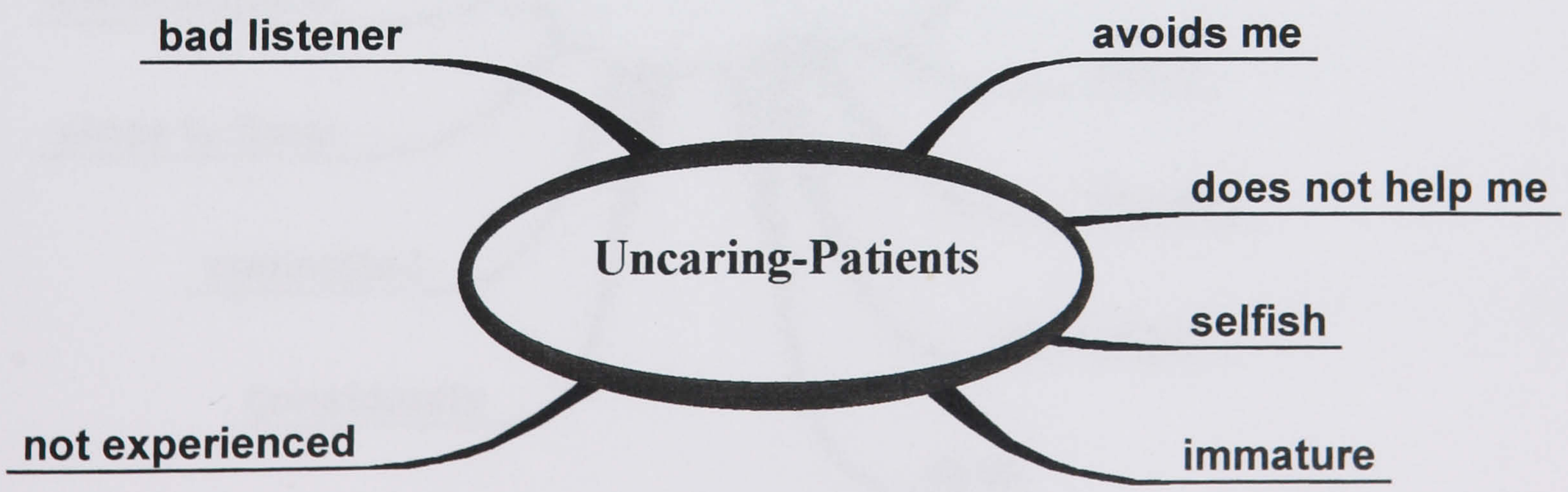
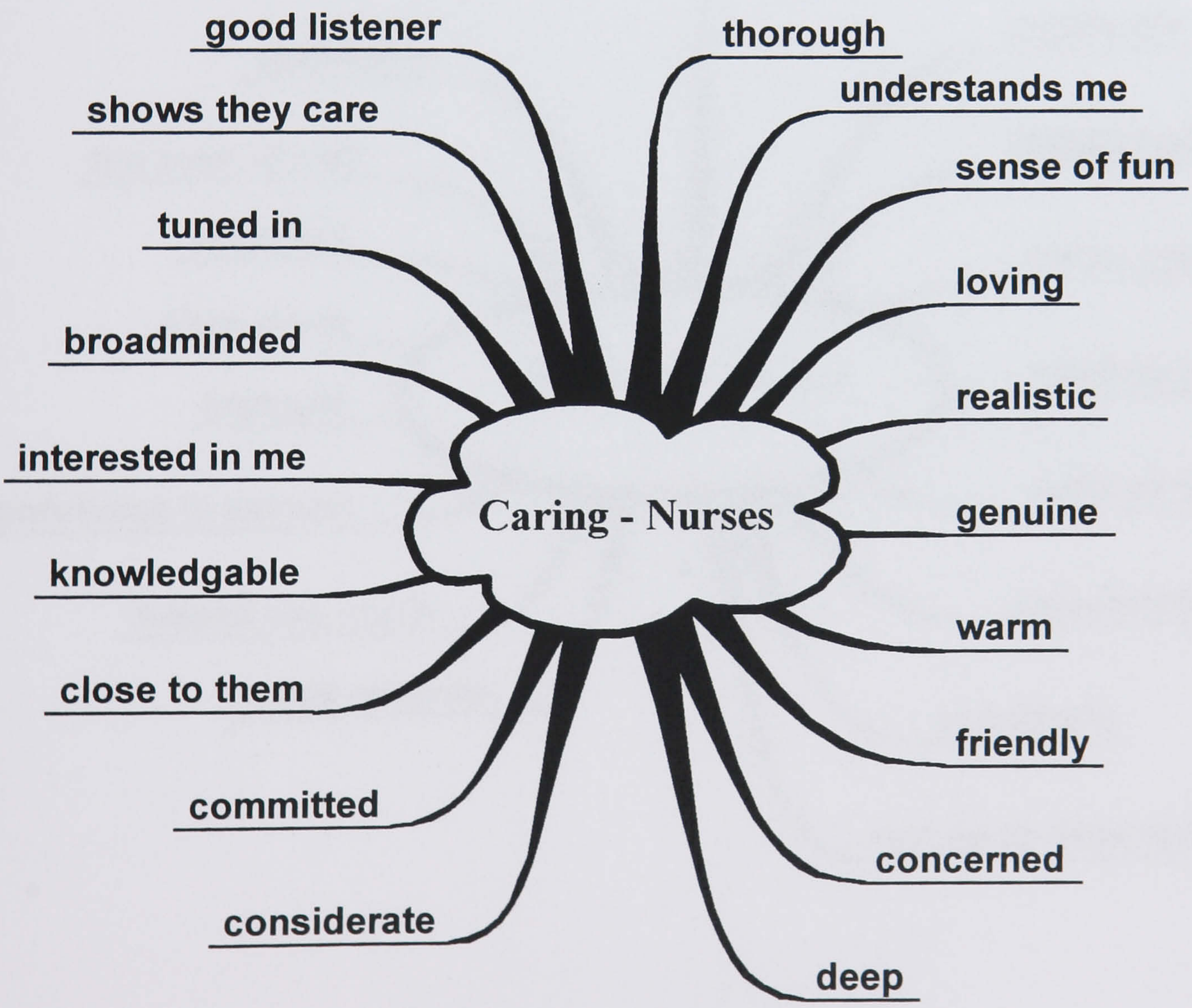


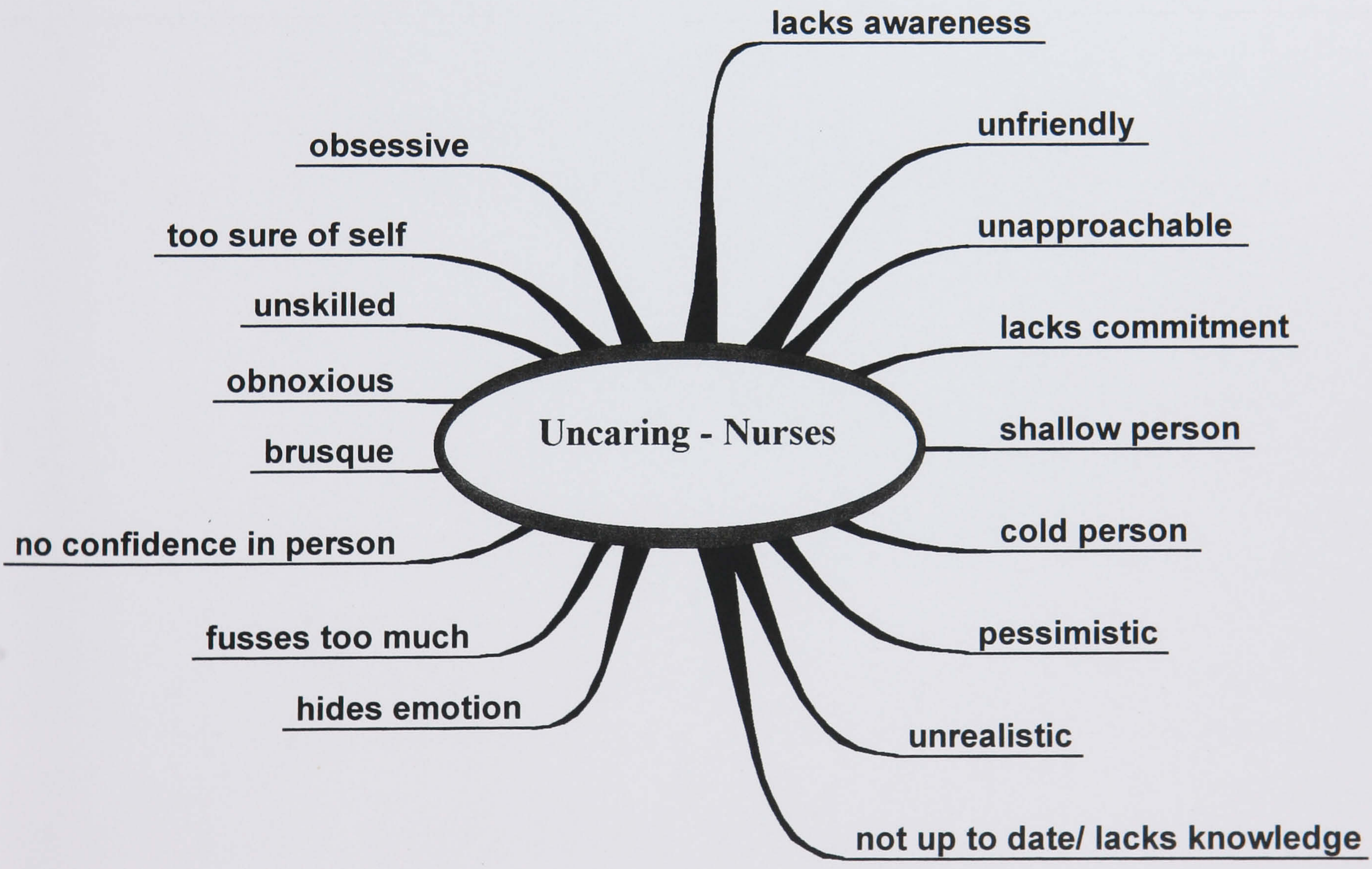
Figure 19 indicates conceptually the key good caring characteristics as perceived by the nurse sample drawn mainly from the repertory grid data. The larger concept map from the nurses' perceptions of caring reflects the smaller patient sample who completed repertory grids. Like the patients' data, several characteristics relate to the personal attributes of carers such as 'broad minded', 'loving', 'warm', 'friendly', 'genuine', 'considerate', 'concerned', 'deep' and has a 'sense of fun'. Professional caring characteristics elicited were 'thorough', 'show they care', 'knowledgeable', 'committed'. Interpersonal characteristics elicited were 'tuned in' and 'good listener'. Like the patients, the nurses identified good carers in the repertory grids as being 'close to them' and 'understanding them'.

Figure 19 Diagram representing nurses' perceptions of good caring characteristics



On the other hand, Figure 20 depicts the nurses' perceptions of uncaring characteristics. Again, the majority of the uncaring characteristics are opposite to the good caring characteristics. The majority of uncaring characteristics related to the personal attributes of carers such as 'obsessive', 'too sure of self', 'obnoxious', 'brusque', unfriendly', 'shallow person', 'cold person', 'pessimistic' and 'unrealistic'. Those uncaring activities related to the unprofessional nature of the carers were 'fusses too much', 'lacks commitment', 'not up to date' and 'lacks knowledge'. Finally, the characteristics related to carers' lack of interpersonal skills were, 'hides emotion', 'no confidence in person', 'lacks awareness' and 'unapproachable'.

Figure 20 Diagram representing nurses' perceptions of uncaring characteristics



6.7.3 Summary of triangulation of findings

Section 6.7 details the triangulation of the findings from both the in-depth interviews and the repertory grids by presenting them diagrammatically. It is demonstrated that the repertory grid findings enhanced the findings from the in-depth interviews by complementing them, particularly in relation to the attributes and characteristics of good nurses as well as the components of effective and ineffective care.

Chapter 7 Discussion

7.0 Introduction

This discussion is structured using the format of answering the research questions, outlining the study's statement of principal findings and presenting key messages. The strengths and weaknesses of this study are explored within a discussion of the methodology and conduct of the study. The issues identified in the findings are reflected upon at a micro and macro level. This includes what the findings meant, highlights new findings and identifies findings previously alluded to in the literature. Subsequently, conclusions and recommendations for practice, education and research are drawn.

7.1 Discussion of methodology

Although the methods used in the study were robust and systematic, undoubtedly there were also some pitfalls and problems. These are discussed and conclusions drawn, demonstrating that despite some limitations this study adopted a unique and worthwhile design.

One strength of the study is that it used an innovative methodology. Repertory grids have not been used previously in conjunction with in-depth interviews to explore dying patients' and palliative nurses' perceptions of palliative care. This combination of methodologies, in the form of methodological triangulation, allowed a holistic picture to develop of the role of the nurse in palliative care and an exploration of the concept of caring in palliative care. This researcher is of the opinion – reinforced by informal feedback on the findings and presentation of the methodology and findings at research conferences - that the combination of methodologies enhanced the study and provided greater depth to the findings, particularly regarding the characteristics and attributes of a good nurse.

The researcher attempted to adhere to the principles of each of the methods used. In this way, the study was theoretically grounded (Corner 1991). For instance, the researcher adhered to the principles of phenomenology as it has been applied to nursing (Benner 1994; Koch 1994; 1999; Cohen and Omery 1994). Furthermore, the

use of the repertory grids was in keeping with the philosophy of the original personal construct theory (Kelly 1955; Winter 1992).

However, by combining complex methodologies, there is a danger of not utilising each methodology to its full effect (see section 3.5). This is particularly true for interpretative phenomenology. To capture the lived experience of informants, it is usually necessary to conduct multiple interviews with each informant (Benner 1994; Koch 1996; Crotty 1996). This was not possible in this study due to the large sample size, combination of methodologies and, most importantly, due to the deteriorating health of the patient population. Moreover, as indicated earlier (section 3.2.2), an adapted phenomenological method was used for this study. As with many nursing studies, particularly those using methodological triangulation (see Rose 1999 for a detailed account of the pitfalls and strengths of using phenomenology with a quantitative tool in her study), it is difficult to keep to the 'true' phenomenological method. However, this research did use the principles of a phenomenological method and demonstrated that this can be achieved in a mixed method study.

The use of in-depth interviews allowed both nurses and patients to 'tell their stories' in keeping with the principles of a phenomenological perspective (Benner 1994). There are however pitfalls of using in-depth interviews. For instance, there is a danger of forming an involving relationship with participants, which can lead to bias (see section 3.3.1). Undoubtedly, the researcher formed a relationship with participants, both nurses and patients. In addition, her personality and previous clinical experience in palliative nursing may well have influenced the conduct and outcome of the interviews. The author, however, believes that these elements, instead of being a weakness, may well have enhanced the study by keeping to the nature of a phenomenological interview. In a phenomenological interview a partnership between researcher and participant is vital for the interview process and the description and interpretation of informants lived experience (Bergum 1991; Benner 1994).

The use of repertory grids enabled an objective data collection tool to be combined with a subjective data collection tool. The RGT also allowed for a more detailed exploration of the concept of palliative caring, particularly in relation to caring

characteristics. In addition, by combining elicited and supplied constructs of caring, a deeper exploration of issues such as 'someone I can talk to' was developed. However, the grids were not without some shortcomings. The small sample size, particularly of the patient sample requires the grid results to be taken in context. For this reason and because of the grid's ability to provide verification and rigor of the in-depth interviews, the qualitative findings may be seen as potentially more valuable than the statistical findings.

Nevertheless, it is argued that the data collected from both in-depth interview and RGT were sufficiently robust for each to have been a stand-alone study. The tools did not function as two stand-alone tools, rather as two complementary, synergistic tools. The grids were enhanced by having data from the interviews which could then be explored in more depth. The grid data validated and augmented the in-depth interview data by enabling issues, such as, caring characteristics to be explored in more detail. Moreover, by utilising two very different methods, the researcher had to carry out more background reading and research related to methodology. This significantly increased the researcher's knowledge and understanding.

Another strength of the study is that the sample consisted of both cancer patients and those patients dying from non-malignant disease. It is rare for palliative care studies to combine dying patients from both groups, even though there is a move in specialist palliative care to include services for patients with non-malignant disease (see section 4.4). In addition, the nurse sample was drawn from both specialist (hospice) and non- specialist areas (acute hospitals) (see section 4.3).

The issue of 'gate keeping', where the nurses were reluctant to refer patients for the study, could have affected data collection and could therefore be considered another limitation of the study. The difficulties inherent when accessing patients may have detracted from the effort to match nurse-patient pairs. When encouraged to refer patients, the nurse may not have referred a patient with whom they had a significant relationship.

The problems with sample attrition which led to a difference in sample size between nurses and patients for the RGT also affected the study. For a mainly qualitative

study, the sample size of 44 informants was large. However, this sample size was chosen to include a suitable sample size for the repertory grids. Moreover, although sample attrition of dying patients is indicative of palliative care research, (see section 2.2.4) a small sample made drawing comparisons between the repertory grids more difficult. The issue of sample attrition and inclusion criteria could not have been avoided due to the nature of the patients' illness. Nevertheless, measures that could have helped include a shorter gap between some of the interviews and the repertory grids conducted as the first interview. However, this would have gone against the philosophy of the study where the beginning of the in-depth interview served to put the patient at ease and encouraged a rapport to develop between researcher and patient. More could have been made of comparing the samples of patients with cancer and non-malignant disease. This would only have been possible, however, if more patients had been recruited with non-malignant diseases.

Dying patients have rarely been asked about their opinions of their care and never before about their perceptions of a 'good palliative care nurse'. This study was, therefore, ground breaking in that respect. In addition, all the patients stated that they had benefited from the experience of participating in the study, signifying the importance of asking dying patients their opinions of their care and including them as research informants in other studies.

Another limitation of the study is the difference in amounts of nurse and patient data for the in-depth interviews (see Table 17). There are several possible reasons for this. Firstly, there may have been a difference in the way that the researcher approached the interviewees. She made an effort to establish a rapport, particularly with the patients. Secondly, the patients were more likely to have time available to spend with the researcher than the nurses. Indeed, on average the patient interviews were significantly longer than the nurse interviews (nurses- 30 minutes, patients- 60 minutes). Thirdly, the nurse interviews were also all conducted in their place of work, normally in their work time. They may have felt therefore that they needed to hurry interviews in order to return to work. The researcher, however, was not aware of any hurried interviews. Finally, the data may have been more compressed for the nurses, in that the researcher felt that the patients had a stronger message to give.

All the research questions were answered. The findings that may be most important and relevant for practice are the characteristics of a good nurse in palliative care, and the findings related to what constitutes palliative nursing care. Although, the research questions were answered, as with many studies of this kind, more questions were raised in relation to a 'good nurse', caring characteristics and developing a framework for practice.

Nevertheless, the strengths of using this research methodology outweighed the problems. The outcome was a worthwhile study highlighting new evidence and substantiating previously held evidence in the field of palliative nursing.

7.2 Caring characteristics

Personal characteristics

As indicated in the diagrams (Figures 17-20, Chapter 6) both patients and nurses rated personal characteristics of caring (such as being warm kind and compassionate), especially in relation to 'good nurse' carers, particularly highly in the repertory grids. This finding is new, in that personal characteristics have not been alluded to before as essential characteristics of a good nurse in palliative care, by both patients and nurses. However, this finding is illuminated by the general and other specialist nursing caring literature. For instance, Morrison's (1991) repertory grid study of nurses' perceptions of caring (see section 2.5, section 3.4.4) found that many nurses used constructs related to personal qualities such as 'kind', 'patient', 'helpful' and 'genuine' to describe their perception of caring. These findings are remarkably similar to the nurses' elicited constructs in this study. This may suggest that caring as a process may have little to do with training and experience and considerably more to do with the personal traits and characteristics which individuals bring with them into the discipline of nursing. This is particularly so for a speciality like death and dying which has as its hallmark the cliché 'tender loving care'. The characteristics may have been rated highly because patients and nurses believe that these are important attributes of caring, particularly when dealing with dying patients, and, because they are not taught or come with experience, that they should be more highly valued.

In addition, Poole and Rowat (1994) (see section 2.5) explored the issue of caring characteristics further in their Canadian descriptive case study of elderly nursing home clients' perceptions of nursing staff. They identified that the largest number of nurse caring behaviours reported by clients related to general, personal attributes of the nurse such as 'good mood', 'understanding', and 'genuineness'. Interestingly, patients also rated these personal attributes more highly than the giving of physical care, as in this study.

Furthermore, in his phenomenological study of patients' experiences of nurses' reassurance, Fareed (1996) endorsed the notion of the importance of a 'good nurse' having personal qualities and attributes. The majority of his patient informants mentioned specific humanistic, personal qualities of the nurses, which played a part in conveying a sense of reassurance by making patients feel at ease.

However, this high rating of personal qualities by patients is not universally acknowledged in the literature (see section 2.5). In Von Essen and Sjoden's (1991) quantitative study using the CARE Q Q-sort instrument, patients most valued clinical competence, while Lauer et al (1982) identified that cancer patients were primarily concerned about minimising side-effects of treatment.

Family caring

Another novel finding relates to how family members were rated most often as good carers by both nurses and patients, indicating the importance patients and nurses (when thinking of themselves as patients) place on the role of family members in caring and supporting terminally ill patients. In fact, the repertory grid findings indicated that the best rated carer by both nurses and patients was, in the majority of cases, a family member or friend. This is despite the fact that many patients indicated that they did not want to be a burden. Although, this seems somewhat inconsistent, it is not altogether surprising that most people would prefer to be cared for by someone who knows and loves them. This is further endorsed by the fact that many of the patients in both the in-depth interviews and repertory grids stated that it was very important to them that the nurse knew them as a person and understood them (section 7.5). What is particularly interesting as far as the implementation and utilisation of the findings is concerned, is that caring and knowing me as person was

by implication more important than professional knowledge, experience and technical skill.

This researcher argues that one of the reasons that informants wanted family and friends above professional carers looking after them is that physical deterioration makes the individual more vulnerable. Moreover, this physical change means that people are often treated differently by strangers and this includes professional carers. Family members and friends, on the other hand, will treat the person as they have always been, rather than the person they have become. In addition, family care is based on a special type of long term reciprocal relationship, unlike a professional caring relationship. This, therefore, may make it a more satisfying relationship.

It was difficult to find evidence from previous literature to illuminate or conflict with this finding. This is despite the fact that in practice, families are increasingly caring for terminally ill relatives, particularly at home (Ramirez, Addington-Hall and Richards 1998). Literature on families and caring was therefore scrutinised. This literature was not included in the literature review (see section 2.3 for an explanation).

Firstly, the literature on family care makes an important conceptual distinction between caring about someone (the emotional meaning of caring) and caring for someone (the tasks or work of caring) (Yates 1999). When caring about someone, such as in family relationships, the situation is therefore subjective and motivated by emotional attachment. Family caring is, therefore, very different from caring by professionals whose ties with the person are qualitatively different. Moreover, family caring is based on lay knowledge rather than professional scientific knowledge. In addition, family caring often involves a long-term commitment. All these differences, therefore, require family caring to be taken seriously by professionals and that families are provided with the information and support they need in order to care effectively.

The research that has been done with family and informal carers of dying patients is mainly in relation to their perceptions of care (Hull 1991), their concerns and needs (Harrington, Lackey, Gates 1996; Payne, et al 1999) and their satisfaction with care

(Field et al 1992; Sykes et al 1992; Kristjanson, Sloan, Dudgeon, Adaskin 1996; Fakhoury, McCarthy, Addington-Hall 1997; Seale and Kelly 1997; Ingleton 1999; Beaver, Luker, Woods 2000).

The literature, therefore, demonstrated that families perceive that hospice nurses are more caring, open, relaxed and attentive than hospice nurses. The behaviours and qualities that identified hospice nurses as a source of caring support were 24-hour accountability and availability, effective communication skills, as well as a caring and non-judgmental attitude. Families concerns and needs were in the areas of information about: symptoms, how to care for the patient, prognosis, and services available. Families also needed emotional and psychological support. Families were usually satisfied with care. However, they did have unmet needs related to a lack of information, support, missed opportunity to say goodbye to their loved one, and perceived uncontrolled pain and symptoms in the dying patient. Although, there was some consensus in patient and family views of care they differed in the areas of presence and absence of physical symptoms, emotional reaction and emotional state of the patient.

These studies suggest that families are dramatically affected by a terminal diagnosis, which is disruptive and stressful, and has a pervasive impact on many dimensions of the family members life. Moreover, some family members may feel forced to take on aspects of a caring role for which they may not feel capable. They may also persist at the role after it has reached a point at which it may be detrimental to their own wellbeing.

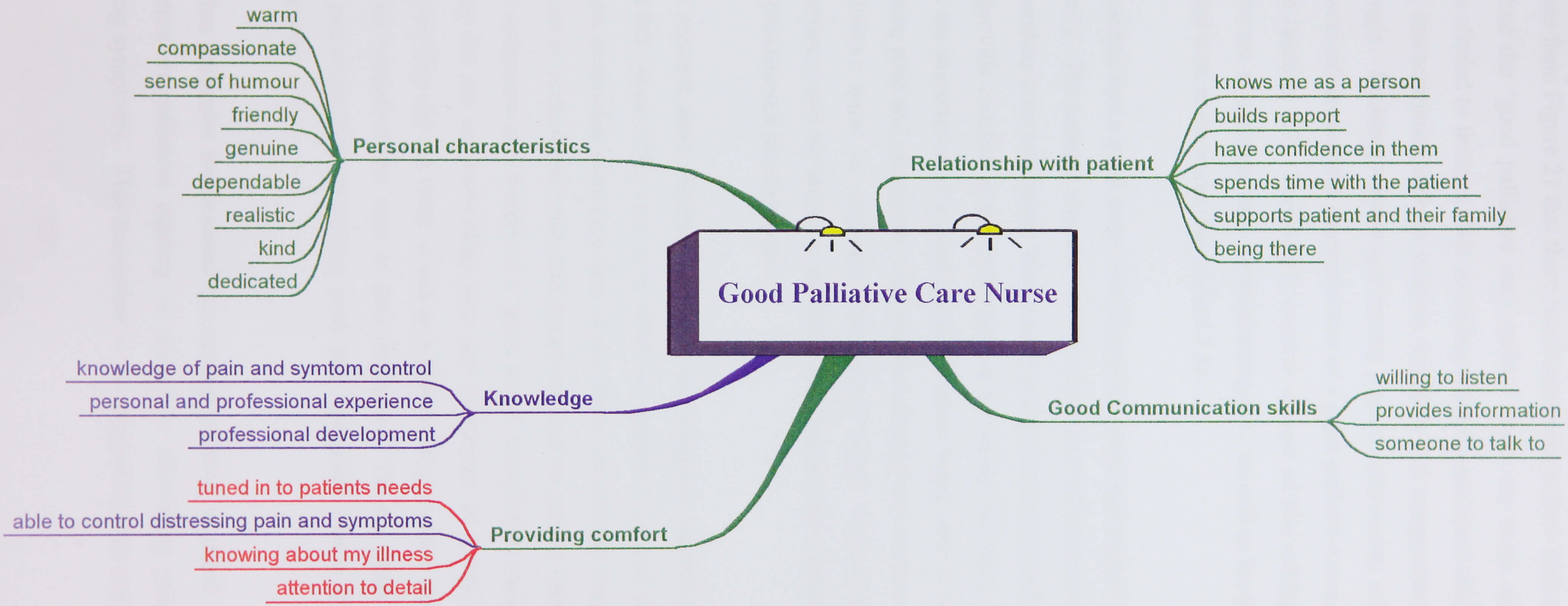
Finally, without the support of family and friends, it would be impossible for patients to remain at home when seriously ill or dying. In the researcher's experience specialist palliative care units, but not necessarily acute hospitals, encourage families to participate in care and to stay with their loved ones, if they wish, when they are seriously ill or dying. Many hospices have family rooms and extra beds for this purpose. Informal caregivers ought to receive information, advice and support before taking on the burdens and rewards of caring for a loved one who is dying. Family members need to be supported in caring for their loved ones and included, if they wish, in direct caregiving in hospitals and hospices.

7.3 Good nurse

Eliciting patients' and nurses' views of a 'good palliative care nurse' was a key objective for this study and one that provided important findings which are pertinent for palliative nursing practice and education. Figure 21 conceptualises these findings diagrammatically.

Figure 21 Diagram representing nurses' and patients' perceptions of a good nurse in palliative care

Key- Green represents patients' and nurses' perceptions of a good nurse
Blue represents nurses' perceptions of a good nurse
Red represents patients' perceptions of a good nurse



It is interesting to note from Figure 21 that there much consensus in how both nurses and patients described the 'good palliative care nurse'. Both the nurse and the patient study sample alluded to features such as having good interpersonal skills and possessing personal characteristics such as warmth, kindness and compassion most often and most strongly. Building rapport and having a good relationship with the patient were also perceived as essential characteristics of a good palliative care nurse by the study sample (section 7.5). Particularly notable aspects of this relationship were 'getting to know me as a person' and 'understanding me', as well as the patient having confidence and trust in the nurse (see section 7.5).

The nurse sample asserted that a good nurse should provide emotional support to the patient and their family. The patients also stressed the importance of the nurse being there for them by spending time with them. Both nurses and patients perceived that a good nurse should provide comfort to the dying patient by tuning into their needs. The nurses stressed the importance of a good palliative nurse being able to control the patient's distressing pain and symptoms. The nurses indicated that a nurse could not be a good palliative nurse or maintain their expert status without having knowledge and experience, and the ability to maintain and improve their knowledge through continuous professional development.

Patients in previous research have alluded to the pain and symptom control role of the nurse (Bergen 1992; Hunt 1992; Cox et al 1993 see section 2.2.4 and section 2.3.6). It is, therefore, somewhat surprising that, in this study, no patients discussed the ability of the nurse to control their pain and symptoms and no patient identified controlling pain and symptoms as a feature of a 'good nurse' in palliative care. This may be because they did not see controlling pain and symptoms as a role of the nurse, or it may be that they did not think of this as a feature because their pain and symptoms were under control at the time of data collection. On the other hand, patients may have perceived that controlling pain and symptoms was a medical rather than a nursing role.

This novel finding has particular implications for nursing practice, as much of the training and education in palliative nursing is related to alleviating pain and controlling distressing symptoms. This researcher is not suggesting that nurses do

not still need to learn about, and understand, pain and symptom control, in order to function effectively as a specialist palliative nurse. She does, however, suggest that this training should be tempered with equal emphasis on the psychosocial role of the palliative nurse, and in particular, the role of effective communication and caring characteristics.

These findings related to the good nurse are new in that no previous studies have identified the attributes and characteristics of a good palliative care nurse from both nurses' and patients' viewpoint. There is however a small body of evidence from nurse informants to confirm these findings (see section 2.3.1) (Degner et al 1991; McClement and Degner 1995; Zerwekh 1995).

Although both of Degner's studies alluded to the importance of having good interpersonal skills in developing expert nursing practice with the themes 'responding to anger' and 'responding to the family', communication skills were not indicated as a hallmark or key feature of expert nursing practice in palliative care. Moreover, no mention was made of personal characteristics of the nurse. Interestingly, the acquisition of knowledge and the maintenance of professional development were not mentioned. This may be because the study was concerned with critical nursing *behaviours* involved in caring for dying patients.

'Connecting' in Zerwekh's study (section 2.3.1) referred to the process of 'joining with patients and loved ones to permit caregiving'. 'Connecting' in this study (section 5.4) formed the core of how both nurses and patients viewed palliative nursing and the role of the good palliative nurse and linked the concept of interpersonal communication with the building of a nurse-patient relationship. Zerwekh indicated that hospice nurses required 'exquisite listening skills', as in this study. The other comparable dimension in Zerwekh's study with this study was the theme category 'comforting' which referred to the nurse having an understanding of alterations in comfort, the means to comfort and the ability to assess the patient's current level of comfort.

Nevertheless, both Degner et al (1991), McClement and Degner (1995) and Zerwekh's (1995) studies were conducted in North America and none of the studies explored the notion of expertise in palliative nursing from the patients' perspective.

The unique findings from this study in relation to a good nurse, therefore, also include all the characteristics identified by patients, as no studies have previously asked patients for their views of a good palliative nurse. Moreover, as identified in the literature review (section 2.2.1) only one previous study ascertained patients' views of their palliative nursing care (Arblaster et al 1990), where patients recounted the importance of nurses being responsive to their needs. This dearth of literature regarding patients' views of their nursing care reveals an important omission from previous literature. Indeed, it has already been identified that dying patients are rarely asked for their views of their care (section 2.2), and that researchers are now identifying this problem and beginning to tackle it (Field, Clark, Corner, Davis 2001).

Moreover, none of the previous studies that explored the role of a good/expert palliative nurse identified that knowledge, professional development, and experience are important components of the good palliative nurse, as identified in this research. However, this finding is not entirely unique to this study. Indeed Benner's (1984) definition states that- 'the expert nurse, with an enormous background of experience, now has an intuitive grasp of each situation and zeroes in on the accurate region of the problem' (p. 32). Benner also identified the importance of the expert nurse possessing practical as well as theoretical knowledge- 'expertise is 'developed only when the clinician tests and refines theoretical and practical knowledge in actual clinical situations' (p. 294). Other researchers exploring the role of the expert nurse have also found from nurse informants, the importance of knowledge and experience in becoming an expert nurse (see section 2.3.1).

The model of a good palliative nurse, therefore, contains five separate but interwoven dimensions: personal caring characteristics, knowledge, providing comfort; nurse-patient relationship and good communication skills. The majority of these are comfort and caring dimensions with effective communication as the key. The psychosocial dimensions, therefore, appear to be valued above technical or

complex skill elements. This researcher would, therefore, argue that this has significant implications for nursing practice as well as education and training.

7.4 Interpersonal- skills- the importance for the good palliative nurse

Both the in-depth interview and repertory grid findings indicate that interpersonal skills are an essential component of the role of the palliative nurse. The key finding is that the good palliative nurse should possess effective listening skills. Indeed, most participants identified this as one of the most important characteristics of a good palliative nurse. Other aspects perceived as meaningful, particularly from the patients' viewpoint, in terms of interpersonal skills were the importance of palliative nurses being available. Patients specifically identified the importance of having someone to talk to when they were low, or had just received bad news. Another key communication skill, mainly identified by the nurses, was the significance of providing information to dying patients, about their prognosis, diagnosis, and any treatment that they were receiving.

As noted in Chapter Two section 2.3.5, the importance of nurse-patient communication with dying patients has been identified in other palliative nursing studies. Although, all these studies on the role of the palliative nurse identified that interpersonal communication was a key aspect of the role of the palliative nurse, none of these studies explored the concept in great depth. In addition all of these studies used nurse informants. Indeed, the only study to explore patient views of their palliative nursing care found that patients did not want the nurse to talk to them about death and dying (Arblaster et al 1990).

This, then, was an important new finding, that patients not only wanted nurses to talk to them, particularly when they were upset or low, but that they perceived interpersonal communication and, in particular, the ability to be willing to listen as an essential prerequisite of a good palliative nurse. This has far reaching implications for palliative nursing practice, especially as studies have revealed that communication by nurses and other health professionals with dying patients is often identified as poor (Wilkinson 1991; Booth et al 1996; Heaven and Maguire 1996). Effective communication skills should, therefore, be an essential requirement for

those nurses wishing to specialise in palliative care and that palliative nurses should all receive some form of communication skills training.

Moreover, few studies have asked dying patients for their views about communication with nurses and whether patients wanted to express their concerns to nurses (section 2.2.5, see also Jarrett and Payne 1995 for a literature review of nurse-patient communication). However, despite the volume of literature indicating that nurses often communicate poorly with patients, much of the research appears to make assumptions about nurse-patient interactions, particularly about what is happening and why. Nurses are sometimes given the chance to explain their actions and give their views (Wilkinson 1991) but patients are rarely given this opportunity. Nevertheless, only Bailey and Wilkinson's (1998) study actually asked patients for their views on nurse-patient interaction. Yet, implicit in the studies of nurses' communication skills is the notion that all patients want to tell nurses their concerns and will do so provided the nurse encourages, and does not block, them.

It could also be argued that effective communication is a particularly important issue in palliative care. Patients with a diagnosis of a life-threatening illness and those who are dying are likely to require a practitioner who can sensitively assess their needs and provide appropriate support when it is required. Hence, although this finding is not unique, it has a particular meaningfulness for palliative nursing care.

It is pertinent to consider that if effective communication skills are so important in palliative care, how they can be assessed. Yet, despite the fact that communication skills are often indicated to be important in nursing there is little evidence about the best way to assess nurse-patient communication skills. The majority of evidence is related to teaching communication skills and evaluating the effectiveness of teaching (Faulkner 1992; Booth 1993; Andrew 1996; Heaven and Maguire 1996, 1997; Wilkinson et al 1998; Wilkinson et al 1999; Booth et al 1999). Evaluation of skills usually consists of analysis of audio-taped interactions and feedback using a rating manual to examine different elements of interaction, with a focus on content and structure, as well as experiential workshops involving role-play and feedback. However, although these methods have been shown to be effective in training nurses and other health professionals (Heaven and Maguire 1996; Wilkinson et al 1999 see

section 2.3.5) they have not been used to recruit nurses or assess nurses when applying for a job in palliative nursing.

The findings that good palliative nurses require effective interpersonal skills and that palliative care cannot be effective without good communication does not just apply to palliative nursing care. Indeed, it could be argued that all areas of nursing practice require nurses to be effective communicators. For this reason communication skills are part of the pre-registration nursing curriculum. However, as identified earlier nurses do not always communicate effectively with patients and their families, indicating that communication skills training, both formally in terms of courses and informally in terms of practice, is an important area for practice and future research.

Willing to listen

'Willing to listen' was the characteristic that nearly all nurse and patient informants perceived to be the most important characteristic of a good nurse in palliative care.. There are other studies related to caring in nursing that have endorsed 'willing to listen' as an important feature of caring in nursing in general (see section 2.5 Larson 1986; Komorita et al 1991; Von Essen and Sjoden 1991; Bailey and Wilkinson 1998; Wells 1998). As well as in palliative nursing in particular (Ryan 1992; Zerwekh 1995). These all, however, had only nurse respondents.

Webb and Hope (1995) and Bailey and Wilkinson (1998) have also indicated that previously patients identified listening skills as a high priority. For instance, Webb and Hope (1995), in their study eliciting patients' opinions of nursing, discovered that patients ranked 'listening to patients' worries' as the most important caring activity. Bailey and Wilkinson (1998) endorsed this view by identifying that the qualities attributed to a good communicator were integral to the patients' perceptions of a good nurse. Part of this view of a 'good communicator' was a 'good listener'.

This researcher, therefore, believes that listening is the single most important communication skill and that effective communication and caring for dying patients cannot occur without skilled listening.

Someone to talk to

The majority of patient informants identified having someone to talk to as an essential part of their palliative nursing care. This was particularly evident when patients were recounting incidents of receiving bad news. Moreover, 'someone to talk to' was the highest-rated construct in the repertory grids, denoting the importance that both patients and nurses attributed to having someone to talk to as a component of good palliative nursing.

The patients, in this study, also affirmed that poor encounters with nurses and other health professionals were often centred on their diagnosis being told to them. They indicated that they often they felt avoided and isolated at this time. This finding is in line with the previous findings of Seale (1991a), Faulkner (1992) May (1993) and Chan and Woodruff (1997). Indeed, Faulkner and Maguire (1994) and Booth et al (1996) argued that patients' psychological concerns are often dealt with inadequately by nurses. This could be because patients find confessing their psychological concerns difficult. Although, this did not seem to be the case in this study. Patients wanted to discuss their concerns and feelings with nurses and expected the nurse to be able to listen to them, spend time with them and be there for them when they were distressed or just needed someone to talk to.

Providing information

Another key finding centred on the issue of the nurse providing information, particularly about the patient's illness. The nurses considered this to be particularly important, although it was an issue that was also raised by some of the patients. This is in contradiction to the work of Payne (1991) who found that many women receiving palliative care for cancer believed that nurses had limited information and knowledge. However, various studies have affirmed the importance of the nurse being able to provide accurate information to the dying patient and their family (Seale 1991a; Hansen 1994; Foshbinder 1994; Krishnasamy 1996; Addington-Hall et al 1995; Rose 1999 see section 2.5). For instance, Foshbinder (1994), in her ethnographic study of patients' perceptions of nursing care, found that patients identified 'receiving information' as a primary activity of the nurse's caring behaviour.

However, despite patients and relatives identifying 'providing information' as a key caring characteristic of the nurse, several studies have endorsed the findings of this study that although information is required, it is sometimes not given. For example, Addington-Hall et al (1995), in their retrospective study, argued that relatives were generally unhappy about the level of information they received in relation to dying patients. Likewise, Rose (1999), in her study of the information needs of informal carers of terminally ill patients, proposed that carers felt the need for information in relationship to the patients' illness. When they understood details about the illness, they were more able to cope with caring for the patient.

7.5 Nurse-patient relationship

The importance of the nurse-patient relationship as a component of a good palliative nurse was another key finding for this study. In particular, important aspects of the relationship, identified by nurses and patients, involved the nurse being there for the patient, building a rapport with them, spending time with them, and knowing the patient as a person.

For this study the nurse-patient relationship was encapsulated by connecting. The nurse used her interpersonal skills to connect with the patient and build a rapport with them, when that rapport was established, then a therapeutic relationship could be achieved. Both patients and nurses acknowledged that they did not connect with all patients and with some patients this took longer than others. Nurses found that they usually connected with a patient when they were their admitting nurse or the patient's named nurse. Patients found that they connected with a nurse when they had something in common, or when the nurse made a special effort to get to know them as a person.

Other studies on the role of the palliative nurse from the nurses' viewpoint, have illuminated this finding by identifying the importance of the nurse-patient relationship in palliative care (Davies and O'Berle 1990; Zerwekh 1995; Rasmussen et al 1995; Byrne and McMurray 1997; Taylor et al 1997; Larkin 1998 see section 2.3). Fewer studies have identified the importance of the nurse-patient relationship from the dying patient's viewpoint (section 2.2.2, section 2.4, Raudonis 1993; Cox et al 1993). Moreover, the Raudonis study specifically asked patients about their

empathic relationships with nurses. The lack of evidence related to patients' perceptions of the nurse-patient relationship reflects the small number of studies that have asked patients for their views of palliative nursing care.

Being there

The issue of the nurse 'being there' is an often underrated aspect of the role of the nurse (Benner 1984; Ray 1991; Roach 1991; Miller and Douglas 1998; Golberg 1998; Minicucci 1998; Deeny and McGuigan 1999 see section 2.5). In this study, it involved the nurse being alongside the patient, using empathic skills, and non-verbal skills such as touch, without necessarily communicating verbally. Interestingly, in this study both nurses and patients alluded to this characteristic. The patient sample indicated that this was a particularly significant aspect of the palliative nurse's role for them. They indicated that they found the mere presence of the nurse comforting, particularly when they were upset, low or had just received bad news. Being there also involved the nurse spending time with the patient, a component of the nurse-patient relationship identified almost universally by the nurses and patients in this study. Spending time with the patient was most often alluded to when the patients and nurses were recounting examples of when they felt time was lacking, or the nurse could have anticipated their needs by spending time with them.

This evidence is endorsed by previous literature on the caring role of the nurse in general or in other specialities (Benner 1984; Miller and Douglas 1998; Golberg 1998; Minicucci 1998; Deeny and McGuigan 1999 see section 2.5). For instance, Benner (1984) identified 'presencing' as one of the eight competencies that reflected the practice domain of the helping role of the expert nurse. Benner maintained that 'presencing' or 'being with' the patient involved touching and allowing the ventilation of feelings without necessarily speaking to the patient, as well as person-person contact among nurses, patients and patients' families. Expert nurses, in turn, reported confidence in the therapeutic effects of 'being with' patients. Benner argued that expert nurses were able to see the value of their presence for their patients.

Furthermore, Oakley (1986) recounted an incident when she was told that she had cancer. She indicated the difference the presence of the nurse made to her. She felt

recognised as a whole person rather than being defined by her illness. Furthermore, in this recognition came relief and healing. Ray (1991) further argued that 'presencing' was about compassionate caring and that this related to a deeper, more authentic relationship, with a sense of being truly present for the other. Continuing with the caring literature, Roach (1991) asserted that 'presencing' by the nurse is enabling for others and that this empowers patients, families, colleagues and staff. She proposed that caring for dying patients involves entering into the experience of others, that it is grounded in the nurse's sense of another human person in need of someone.

'Being there' in both the physical and psychological sense, therefore, enhanced and helped to develop the nurse-patient relationship in this study. The psychological presence of the nurse, in particular, enabled the nurse and patient to establish rapport. This researcher believes that this evidence illuminates the importance of the role of the nurse in the care of the dying patient and helps determine what the nurse does that is different to other health professionals. Nurses are there for the patient 24 hours a day, providing continuity of care. It could be argued that the building of a therapeutic relationship, being there and establishing rapport are specific to the role of the nurse.

Spending time with the patient

Both nurses and patients identified that good palliative nursing care involved spending time with the patient. This is an issue alluded to by many nurses anecdotally, particularly in relation to nurses indicating that they do not have enough time to provide the quality and standard of care to dying patients that they would like to have. This notion has also been suggested in studies related to the concept of caring in general (Forrest 1989; Morrison 1991; Poole and Rowat 1994; Milne and McWilliam 1996). Surprisingly then, this issue has not been previously identified in the palliative nursing literature.

For instance, Milne and McWilliam (1996) found that the overarching structure by which all elements of nursing were connected was 'spending time'. They discovered that time was described by their informants as important moments between nurses and patients. This perspective differed from the objective and linear notions of time.

Patients reported valuing nurses 'spending time' and 'doing for' patients when they were sick or in crisis. Patients valued nurses 'spending time' when they met other patients' and families' needs by providing comfort, support, education and encouragement. Spending time was perceived as 'being there' for the patient, as in this study. Nurses, on the other hand, sometimes experienced difficulties in prioritising their time. Patients also noted that nurses were often too busy to make time for them and that they did not feel they could bother the nurse in this situation.

The patients in this study recounted incidents where they were fearful of calling for help when the nurses appeared to be too busy. When the nurse is working under time constraints, she appears to spend time carrying out physical tasks to the detriment of psychological care. For example, Corner and Wilson-Barnett (1992) found that newly qualified nurses rated their competence of talking with patients quite highly, although not as highly, as the giving of physical care.

So, although the characteristics of being there and spending time with the patients have been identified in previous literature, this finding is novel in that they are not characteristics previously attributed to a good palliative nurse by both nurses and patients.

Knowing me as a person

'Knowing me as a person' and 'understanding me' were key features of the good nurse in palliative care and which emerged from both in-depth interview and repertory grid data. Although, it was the patients who primarily identified these concepts, they were also features that were ranked highly by nurses in the repertory grids when identifying characteristics of good carers. These characteristics, therefore, embodied the importance the patients, in particular, attributed to the nurse-patient relationship.

The patients in this study had all been living with serious illness for some time. There may have been several reasons why 'getting to know me' was viewed as an important characteristic of palliative nursing care as well as the fact that these constructs were rated particularly highly in the repertory grids. For instance, it may have been because the patients felt that they could not trust or establish a rapport

with the nurse unless they understood them or made an effort to get to know them. 'Getting to know me' may also have been rated highly as a reaction to how the patients felt about their illness, and their way of coping with being a 'pawn' in the health care system. The health care system may have previously treated the patient as an illness, a 'dying patient' and not as a person. For the patients, in this study establishing a rapport was also significant, in that, even when their physical body had failed and their appearance had changed, sometimes dramatically, their self and personhood remained.

Although, as indicated earlier the importance of the nurse-patient relationship has been referred to in the palliative nursing literature, this feature of understanding and getting to know the patient has not been alluded to in this way by patients. This may be due to the small number of studies that have asked patients for their views of palliative nursing care and not that this is not an important area of palliative nursing practice.

The feature of getting to know the patient has however been alluded to by nurses in the general or other specialist nursing literature (Forrest 1989; Foshbinder 1994; Lindsey 1996; Milne and McWilliam 1996 see section 2.5). For instance, Forrest, in her phenomenological study of the lived experience of caring by registered nurses, found that nurses talked about the importance of 'knowing the patients well'. Foshbinder (1994), in her study of patients' perceptions of nursing care, found that patients stressed the importance of 'getting to know you' as a important attribute of nurses. In the process of 'getting to know you', 'becoming acquainted', 'personal sharing' and 'being friendly' were all techniques that the nurses engaged in almost continuously. An immediate rapport between nurse and patient facilitated the process of 'getting to know you'.

7.6 Living with a terminal illness

Being in control

A significant feature of the lived experience of the dying patients, in this study, was how they coped with their terminal illness, by maintaining their independence and being in control. Being in control ties in with another feature of the patients' lived experience described earlier (getting to know me); in other words the patients wanted

to remain in control to retain their self worth. They perceived that their illness had made them lose control and independence, often in terms of others having to do things for them, that they normally would have done for themselves. Being in control, even over something seemingly minor, like limiting visitors, or choosing meals, enabled them to preserve and maintain their dignity. This has important implications for nursing practice, particularly as many nurses perceive that providing comfort to patients is an important part of their role for patients, particularly in the last 48 hours of life. Moreover, often when nurses are busy, or working to a task-orientated model of care, they find it is easier to 'do for' patients rather than allow patient to 'do for themselves'. Palliative nurses, therefore, need to consider issues of control and dependence even in the latter stages of an individual's illness and ascertain the degree of independence patients want, and attempt to facilitate this for them. This researcher believes that this requires palliative nurses to be creative in their approach for caring for patients, particularly when their condition has seriously deteriorated, or when they are comatose or unconscious, by carrying out patients' wishes and maintaining and creating their autonomy.

However, issues of dependency and maintaining independence in dying people have rarely been investigated. For instance, Seale and Addington-Hall (1994) suggested that patients who are in the last year of life fear dependency more than they fear pain. They even go so far as to say that this fear of dependency caused patients to request euthanasia. They suggested that their findings, like the findings in this study, had important implications for the hospice movement which needs to extend its expertise developed in the area of pain and symptom control to address the area of dependency). In order to remain self-sufficient and independent of others, Flanangan and Holmes (1999) postulated that a person with a life-threatening illness must be able to engage in self-care activities, and their ability not do this is determined by symptom burden, illness trajectory and the desire to engage in self-care.

Nevertheless, Seale and Addington-Hall (1995) argued that for those patients who are admitted to a hospice, engaging in self-care and being encouraged to maintain their independence might serve to remind them of a decline in ability to do things for themselves. However, nurses can have both a positive and negative influence on the ability of patients to maintain their independence.

Moreover, the evidence for nursing's therapeutic potential in relation to the problem of patients maintaining their independence and being in control remains weak. The current literature represents a shift in the trend of palliative care and hospice care with a growing emphasis and interest in rehabilitation (Hockley 1993; Frank, Hobbs and Stewart 1998). However, Walter (1994) challenged this notion of rehabilitation by arguing that a key function of palliative health care professionals should be focused on helping individuals come to terms with their declining abilities. He proposed that dependency is not a loss but a characteristic that requires a different kind of humanity.

The role of palliative nursing in maintaining patients' independence may, therefore, involve psychosocial care to facilitate acceptance of loss of control, or indeed to facilitate independence for as long as possible, where feasible, by working in partnership with the patient.

Role of the hospice in patients' lives

The lived experience of patients in this study was characterised by the role the hospice played in their lives in terms of enabling them to cope with their terminal illness. The patients perceived the hospice to be a safe place, it made them feel relaxed and secure, and they discussed the 'homely', or 'family' atmosphere. None of the hospital patients made a similar reference to the hospital setting. Obviously, this was an issue only indicated by patients who had come into contact with the hospice, but as patients who did recount this, placed such an emphasis in their stories of the role of the hospice in their lives, it becomes a significant finding. Moreover, this is a novel finding in terms of the lived experience of their palliative nursing care.

Somewhat surprisingly, given that the original function of a hospice was as a place of rest for travellers (Saunders 1999), there is very little reference in the literature to endorse these issues (McDonnell 1989; Seale and Kelly 1997 see section 2.2.2). McDonnell (1989) found that the hospice enabled the patients to be 'peaceful', 'calm' and 'comfortable' and the patients commented on the 'relaxed atmosphere' of the hospice. Seale and Kelly (1997 also found that the hospice was significantly more likely to be viewed as being 'like a family' than the hospital.

Nevertheless, the finding related to the importance of the atmosphere and security of the hospice in dying patients' lives has particular implications for palliative nursing practice. Palliative nurses in general, not just hospice nurses, need to be aware of the importance of creating a safe, secure and homely atmosphere for dying patients. Patients could be encouraged to bring personal effects when they are cared for in an institution to create a homely atmosphere. In the researcher's experience, personal possessions such as photographs, pictures and books can create a less clinical and therefore less frightening environment for the patient. In addition, the nurses could consider patient choice and wishes and maintain their autonomy more creatively. Another feature which may help create this safe, secure and homely atmosphere is how the patient is greeted and approached when they enter the hospice. A warm, friendly, welcome will help put the patient at ease, as will continuity of care in terms of the admitted nurse being their named nurse.

Tight construing

Another feature of living with a terminal illness, and coping with caring for dying patients by nurses is related to the stress of coping with a terminal diagnosis. This was indicated, not in the in-depth interviews but by the RGT, in the way that both nurses and patients exhibited tight construing (see section 6.3). Tightness of constructions may be employed as a defensive strategy to counter anxiety. The person who construes tightly builds a system which is designed to be 'anxiety tight' (Kelly 1955). People who are under stress have been found to be less cognitively complex and construe tightly (Miller 1968). This would certainly help to explain why the patients construed tightly. The patients were all seriously ill and knew that they were dying. Moreover, there is a strong link between anxiety and terminal illness (Kübler-Ross 1969; Hinton 1972; Weisman 1979).

The explanation is somewhat weaker for the nurses. The nurses could be construing tightly as a defensive mechanism. It has been identified in the literature that dealing with death and dying on a daily basis is a stressful activity for nurses (Bene and Foxall 1991; Booth 1995; Vachon 1995; McKee 1995). McKee recommended from the findings of her study, that nurses do not spend longer than three years in direct care giving with palliative care patients without a break, or change, in their role.

Most nurses in this study had been working with dying patients for longer than this period. They may cope with death and dying by either emotionally detaching themselves or conversely becoming too involved, both of which may cause stress and anxiety. Nevertheless, the nurses in the study were not 'obviously' anxious or stressed but perceived their world in an 'anxiety tight' way.

7.7 Comparing practice of palliative nursing with other nursing specialities

No studies have specifically compared palliative nursing as a speciality with other specialist areas of practice. Moreover, there is little evaluation of the specialist nurse in palliative care. However, if some of the findings are to be useable in other care settings, it is worth exploring the similarities and differences between specialist nurses in palliative care and specialist nurses in other areas of practice.

This researcher argues that there are some factors that are unique to the palliative nurse specialist and some factors common to other specialist areas of nursing. Those areas unique to palliative nursing are a body of knowledge related to pain and symptom control (Quint Benoliel 1988; Webber 1993) as well as psychosocial care and loss and grief (Webber 1993). Palliative nurses also have an ability to provide an integration of psychosocial and spiritual care (Stiles 1994; Taylor et al 1999). They also have an ability to prepare patients for death (Field 1989; Brockopp et al 1991; Degner et al 1991) in both a psychological and comfort sense. Palliative nurses may be better at this role than other nurses because they are more likely to have positive attitudes towards death and less death anxiety than nurses in other specialities (Kirscling and Pierce 1982; Bene and Foxall 1991; Payne et al 1998). Bereavement care is also usually a part of the palliative nurses' role that is less likely to be a part of the nurses' role in other nursing specialities (Kindlen 1987; Nash 1992; Bergen 1992; Webber 1993). Palliative nursing is unique, therefore, in the fact that nurses choose to and are therefore more prepared to work with death and dying. Nurses have often thought about their own mortality and may have a personal experience of death and bereavement. Indeed, this may be one of the reasons they choose to work in palliative care.

Those factors held jointly with other nursing specialities include a philosophy of compassionate holistic care. Although this is often acknowledged anecdotally as a

feature unique to palliative nursing, this researcher believes that as there is no evidence to endorse this view, that it is not a feature unique to palliative nursing. Indeed, it is important that holistic care is provided in all areas of nursing. Effective communication is also a skill and attitude that is necessary across all nursing specialities (Bamford and Gibson 2000). Providing emotional support (Bamford and Gibson 2000) and providing education and training to other staff (Webber 1993; Bamford and Gibson 2000) are also components of the nurses' role in all specialities. Problems and difficulties in the role pervade the specialities and include lack of support, isolation, poor time management, role conflict, disempowerment, and burnout (Wilson-Barnett and Beech 1994; Vooght and Richarson 1997; Bousfield 1997). Providing support to families is also not unique to palliative nursing (Bamford and Gibson 2000).

Despite the lack of evidence regarding comparing the palliative nurse's role with the role of the nurse in other areas of practice, this researcher would suggest that aspects of specialist palliative nursing, and therefore some of the findings from this study, are relevant for other specialities, and therefore the wider health care context. These include the importance of the nurse having good interpersonal skills, the importance of having positive personal characteristics and qualities and the importance of the nurse having a positive and reciprocal nurse–patient relationship. In addition, the nurses' role in providing comfort for patients and the importance of providing psychosocial support to the patient and their family is generalisable to all specialist areas. The specific specialist areas for palliative nursing relate to the particular clinical knowledge, experience, and professional qualifications necessary to deliver a high standard of care to dying patients and their families.

7.8 Answering the research questions

What is palliative nursing care from the patient's perspective?

The patients perceived that good palliative nursing care consisted of effective interpersonal skills and caring skills. They were of the opinion that the nurse should meet their needs by helping them, 'being there' for them, providing them with emotional support, being someone to talk to, providing comfort and, most importantly, spending time with them.

What is palliative nursing care from the nurse's perspective?

The nurses considered that palliative nursing care required a cohesive multi-disciplinary team to function effectively. The nurses also attributed much importance to the nurse having knowledge and personal and professional experience. They proposed that the nurse could not provide effective palliative nursing care without providing comfort, which required the ability to relieve pain and control distressing symptoms.

Are there differences between patients' and nurses' perceptions as to what constitutes good palliative nursing care?

Differences in the way patients and nurses perceived good palliative nursing care were identified in the in-depth interview findings (see section 5.12). The patients discussed the need to maintain their independence as well as adopting a fighting spirit as a way of coping with their terminal illness. Those who had been hospice patients identified the importance the hospice, as opposed to the hospital, had in their lives as a place of sanctuary and in making them feel safe and secure. The patients also attributed much significance to the presence of the nurses 'being there' for them, particularly when they were feeling low or vulnerable.

The patients believed that a good nurse in palliative care was kind, compassionate, caring, willing to listen, knew about their illness and provided support to them and their family. They were someone to talk to and they got to know patients as people.

Moreover, the nurses also indicated that a good palliative nurse was willing to listen, caring, able to provide information to the patient and had a sense of humour. The nurses also stated that a good nurse needed to be willing to spend time with the patient and provide support to the patient and their family. They maintained that a good nurse was able to build a trusting relationship with the patient, often just by 'being there' for them.

However, the nurses tended to focus on aspects of knowledge and experience as attributes of good palliative nursing care much more than the patients did. They stated that a good nurse in palliative care should be appropriately qualified, keep up to date and have both personal and professional experience in the care of dying

patients. The nurse sample also believed the good nurse in palliative care needed to retain a sense of humour, which helped them to cope with the emotional strain of caring for dying patients.

What do dying patients identify as characteristics of caring?

Patients agreed that the characteristics of good caring were someone who was kind, dependable, helpful, realistic, experienced, knew them as a person, was interested in them and to whom they could talk in confidence. A discussion of the good and bad caring characteristics identified by the patients can be found in section 6.7

What do nurses caring for dying patients identify as characteristics of caring?

Nurses agreed that the characteristics of good caring were; thorough, thoughtful, considerate, warm, committed, being tuned in, having a sense of humour, being up to date, genuine, a good listener, being able to show they care, being able to feel closeness, being trustworthy and being interested in patients as people. A discussion of the good and bad caring characteristics identified by the nurses can be found in section 6.7

7.9 Overall summary

This chapter has explored the principal findings and key messages from the study in the context of previous literature. The strengths and weaknesses of the study have also been explored, enabling conclusions and recommendations for practice, education and research to be drawn.

Key messages from the study are:

- A 'good nurse' for this group of nurses was someone who is an effective communicator, kind, committed, considerate, warm, knowledgeable and experienced, a good listener, had a sense of humour, provided comfort and support to the patient and their family and was skilled in pain and symptom control (section 5.7; 5.8 in-depth interviews; section 6.2 repertory grids).

- Nurses identified a key feature of a 'good nurse' as being skilled in pain and symptom control (section 5.9.2 and section 5.11.1). None of the patients identified this as feature of a 'good nurse'

- The components of ineffective care from the nurses' viewpoint were poor pain or symptom control, inadequate or poor communication, and lack of time.

- In order to be a 'good nurse' in palliative care, the nurse also needed to 'know what they are doing' and 'work together' as part of a multi-disciplinary team.

- A 'good nurse' for this group of patients was someone who is kind, considerate, dependable, helpful, realistic, a good listener, someone they could talk to, who was interested in them as a person, knew them as a person, spent time with them and was supportive (Figure 21, cross reference section 5.3 in-depth interviews, section 6.2 repertory grids).

- Ineffective palliative care as far as the patients were concerned involved being avoided or kept waiting, poor or ineffective communication, nurses and other health professionals who had a poor attitude or brusque manner, and having staff who were not interested in them.

- Patients expected the nurse to allow them to 'be in control' and to make them feel relaxed, safe and secure whilst a hospice in-patient.

- Patients coped with their terminal illness by remaining in control and by adopting a fighting spirit (section 5.4). Moreover, the hospice played an important role in some patients' lives in terms of making them feel relaxed, safe and secure (section 5.6).

There are unique issues arising from the study related to the role of the palliative nurse. For instance, the way that both patients and nurses viewed a 'good palliative care nurse' in relation to interpersonal skills, personal attributes and the impact of the nurse knowing the patient as a person. Some of the findings have been alluded to in

previous literature on the role of the palliative nurse and caring as a feature of nursing generally. Nevertheless, as mentioned earlier, very few studies have elicited patients' views of the palliative nurse and only one study (section 2.2.5), which was actually a component of a larger study, focused on patients' views of nurses' interpersonal skills. Moreover, no previous studies have identified a 'good palliative care nurse' from the perspective of dying patients. In addition, only one study elicited patients' views of palliative nursing care (section 2.2.1).

- This is the first study to identify a framework of palliative nursing care (Figure 6) and a profile of a good palliative nurse (Figure 21) from the perspective of palliative nurses as well as dying patients.

- Other components of palliative nursing care identified from this study are 'meeting the needs of patients' (section 5.5) by 'providing comfort' (section 5.9).

- An essential element of providing comfort and meeting the needs of the patient involved 'spending time with the patient'.

- The most valued caring characteristics as far as both nurses and patients were concerned were personal or humane characteristics as well as aspects of interpersonal communication (repertory grids section 6.2).

- The cornerstone of palliative nursing care in this study is 'connecting'.

'Connecting' involves good interpersonal skills (in-depth interviews section 5.3 and 5.8; repertory grids section 6.2 and 6.4.3) as well as getting to know the patient as a person (in-depth interviews section 5.3.1 repertory grids section 6.2). Personal attributes of the nurse are also included within connecting (repertory grids section 6.2).

- The majority of both patients and nurses chose a family member or friend as their 'good carer' (the person rated most highly in their grid against the constructs the

informant had chosen) rather than a health professional (repertory grids section 6.5).

Chapter 8 Conclusions and Recommendations

8.0 Conclusions

This study used a unique combination of methodologies to explore the lived experience of patients and nurses regarding palliative care and what they perceived were the characteristics of a good palliative care nurse. The use of the repertory grid technique allowed the nature of caring to be elucidated in detail, particularly in relation to how both patients and nurses perceived the attributes of caring and who they perceived to be good carers.

The findings demonstrated that important characteristics for good nurses were someone who is interpersonally skilled; in particular, that they were willing to listen and were someone they could talk to as well as someone who had personal characteristics such as kindness, warmth and compassion. Caring characteristics, such as spending time with the patient, friendship, providing support, being committed and able to show that they cared were also perceived as important. Another major issue related to the importance of the nurses being interested in the patient as a person and being able to get to know them. The issues of the nurse being knowledgeable and experienced were also described.

Interestingly, nearly all patients and nurses would prefer a family member or friend to be caring for them when they were dying rather than a health professional. As palliative care becomes recognised as a distinct medical speciality, the importance of providing effective pain and symptom control is becoming more apparent and much emphasis is placed on these issues in palliative care courses. Yet, in this study, no patient identified providing effective pain and symptom control as a feature of a good nurse in palliative care.

The lived experience of dying patients was characterised by the need to remain in control and to maintain their independence for as long as possible. It seems that, no matter how dependent the patient may seem to the health professionals, being in control was the last, and most important, aspect that was left in their life.

The role of the hospice in patients' lives was also demonstrated. Patients who had been hospice in-patients perceived the hospice as a 'family', stating that it made them feel safe and secure. The hospital patients did not touch on this aspect of the institution. The patients also indicated the importance of being supported by their family and the nurses who were looking after them. Patients wanted palliative nurses to be there for them by spending time with them, provide comfort by meeting their needs and for nurses to listen to their fears.

The lived experience of palliative nurses was characterised by effective and ineffective interpersonal communication, the building of therapeutic relationships with dying patients, attempting to control pain and distressing symptoms, endeavouring to work as an effective multi-disciplinary team with their colleagues, and developing knowledge and experience in palliative care.

Finally, the nurses in the sample tended to construe their world in a uni-dimensional way. This may because they were stressed or even depressed. However, it is more likely that palliative care nurses adopt a defence mechanism to help them cope with the stress of caring for dying patients on a daily basis.

8.1 Recommendations for practice, research, education

8.1.1 Recommendations for nursing practice

The findings of the study have many implications for the practice of palliative nursing. The findings related to the importance of interpersonal skills, as well as humane and personal characteristics of the nurse, have issues for recruitment in both generalist and specialist palliative care. It is unlikely that nurses will demonstrate these characteristics on their CV. Moreover, it may be difficult to assess these skills in an interview. It may prove beneficial, therefore, to offer the nurse an induction period, of one-two months, during which time s(he) would work with a mentor who could provide feedback on their progress and provide a role model for developing these skills (see also recommendations for education).

As demonstrated in the literature review, there are few frameworks for practice for the palliative care nurse and little guidance on what a good nurse in palliative care is. The model (Figure 7) developed from the findings of this study may prove a useful

tool to guide palliative nursing practice and for practitioners to see how both nurses and patients view a good nurse in palliative care.

The fact that patients and nurses perceived that a family member or friend was the best possible carer for them, and the fact that the characteristics of 'knowing me as person' and 'understanding me' were rated so highly by both nurses and patients, also have profound implications for practice. It follows that nurses could encourage family members to become more involved in caregiving and that more emphasis should be placed on 'getting to know the patient as a person' by developing a rapport and building a relationship with the patient. A family room should also be available for the dying patients' relatives and resources, in terms of information, advice, and support provided.

Nurses working in palliative care are often stressed and in need of staff support. The fact that the nurses in this study construed caring in a uni-dimensional way suggests that 'nurses need caring for, too'. This could be achieved by regular de-briefing sessions with an outside facilitator or implementing a form of rotation that allowed nurses to change their role. For instance, a day-care staff nurse could swap roles with a ward staff nurse, district nurses could swap with home care sisters and hospital staff nurses could swap with hospice staff nurses for a three-six month period.

8.1.2 Recommendations for nursing education

The findings have many implications for nurse education in palliative care. The model and characteristics of a good nurse in palliative care could be used as a framework when designing education programmes in palliative care. The findings also demonstrate the importance of interpersonal skills training for nurses working in both generalist and specialist palliative care. This could be carried out in tandem with emphasising the importance of personal characteristics like warmth, compassion and empathy. The findings also suggest that interpersonal skills training should be mandatory for those nurses who wish to work in specialist palliative care, either as part of a postgraduate or graduate programme in palliative care or as stand-alone courses for those already with a specialist practice qualification. In addition, education about pain and symptom control should be tempered with equal emphasis

on the psychosocial role of the palliative nurse, and in particular, the role of effective communication and caring characteristics.

Indeed, interpersonal skills training should be a pre-requisite for those nurses wishing to specialise in palliative care or as an assessment requirement for nurses in a probationary period before being offered a full-time contract in palliative care. The most beneficial framework for this communication training would be audio-taped feedback, in conjunction with supervised role play.

8.1.3 Recommendations for research

Although it is recognised that there are many problems involved in mixing methodologies, this study does show how mixing two distinct but complementary methodologies can work well. The use of repertory grids, in particular, proved a useful tool when including dying patients as informants and should be used further in this field to explore other issues such as patients' views of their care, feelings about dying and coping regarding their death. The use of phenomenological interviews to explore the lived experience of other aspects of palliative care could also be useful. Further phenomenological studies in this area would benefit from multiple interviews with informants to build up a more substantial insight into their lived experience. In addition, when mixing methodologies, interviews could be used to supply constructs for the repertory grids.

Unanswered questions and issues that emerged from this study include making more effort to match pairs of nurses and patients, particularly in relation to the issue of elucidating how nurses and patients build rapport with each other and the development of the nurse-patient relationship. It would have been interesting to be able to ask patients about the nurse who recommended them and to clarify incidents or experiences with the nurse or patient. This would be easier to carry out in an area where named or team nursing operated, and if a smaller sample size was used.

The issue of how patients cope with their life-threatening illness also requires further exploration. A longitudinal study could be carried out where the patients' experiences could be explored at different stages of their dying journey. In addition, more research is needed into the role the hospice plays in patients' lives. More could

also be made of the comparisons between patients' experiences of hospices and hospitals in their dying experience.

More research is also needs to compare the dying experiences of patients with malignant and non-malignant diseases, particularly in terms of their perceptions of their nursing care. Moreover, few other studies have compared patients' and nurses' experiences of palliative care. This comparison proved useful, both in terms of the reported similarities and differences in terms of how patients and nurses perceived the role of the nurse in palliative care. Patients proved to be good informants and appeared to gain a great deal for themselves from the interview experience. The particular, but inevitable, problem of sample attrition when carrying out data collection on more than one occasion with dying patients needs further thought. Perhaps patients could be interviewed earlier in their dying experience so that multiple interviews would be more likely to be achieved. Patients could also be recruited from day-care or from home care where they may be well enough to complete multiple interviews.

Overall this study has important implications for palliative nursing practice, in particular the recruitment of palliative care nurses, nursing education, specifically, the curriculum for specialist palliative care education and nursing research. It also provides a unique perspective into how both dying patients as well as palliative nurses view palliative nursing care.

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Appendix I Letters re: permission/access for study

Sample letter requesting access

13 A Bank Street
Falkirk
FK1 1NB

Miss X
Director of Nursing
X Hospital/ Hospice

6th July 1995

Dear X

Re: Perceptions Of Nursing Care In Hospices And Hospitals- PhD Study

Thank you for agreeing to meet me on *date* to discuss my PhD study and my request for access to nurses and patients at x hospital/hospice. I have already submitted an application to the x Local Research Ethics Committee which will be considered at the next meeting. I am enclosing my study proposal for your information.

I look forward to meeting you.

Yours sincerely,

BRIDGET IRVINE
LECTURER IN PALLIATIVE CARE

(N.B. Irvine is Bridget Johnston's maiden name)

SAMPLE LETTER GRANTING ACCESS

Ms Bridget Irvine
13 A Bank Street
Falkirk
FK1 1NB

17th August 1995

Dear Ms Irvine

Re: Perceptions Of Nursing Care In Hospices And Hospitals- PhD Study

Thank you for taking the time to explain to me the purpose of your study. Once again, I would wish to reiterate my support and the support of the Trust management board. Providing the Local Research Ethics Committee gives its approval, I am happy for the study to go ahead.

I have identified the following wards as suitable for inclusion in your study. I suggest you contact the ward sister directly who has been informed about your study.

I look forward to receiving a copy of your report on its completion.

Yours sincerely

Miss x
Director of Nursing

Appendix II Ethics committee approval

Cambridge Health Authority
Addenbrooke's Hospital
Hills Road
Cambridge CB2 2QQ
Tel: (0223) 245151

24th January 1994

Ms B Irvine
Education Centre
Hinchingbrooke Hospital
Box 72

Dear Ms Irvine

A STUDY INVESTIGATING NURSES' AND PATIENTS' PERCEPTIONS OF THE FACTORS INFLUENCING THE EFFECTIVENESS OF NURSING CARE OF THE DYING PATIENT AND THEIR FAMILY IN ACUTE AND SPECIALIST HEALTH CARE SETTINGS

Reference No: LREC93/157 **(Please quote on all communications)**

Thank you for clarifying the points raised by the Local Research Ethics Committee (LREC). As agreed by the LREC I am taking Chairman's Action to approve the project.

In reviewing this project the Committee have studied and approved, where applicable, the completed Cambridge Local Research Ethics Committee application form, research protocol, subject information sheet and consent form.

Furthermore, whilst I am sure that every effort is already made to preserve the confidentiality of any patient information you use in this study, could you please ensure that the team of investigators are aware that everyone who has access to patient information appreciates the importance of maintaining confidentiality, particularly in respect of the use of computers, and statutory regulations laid down in the Data Protection Act 1984.

Investigators are reminded that all electromedical equipment, including items purchased or on loan for research purposes, must be safely tested by the Instrument Laboratories, Medical Physics, before they are used. If this project involves the use of any equipment, which has not already been checked please contact Mr x District Biomedical Equipment Manager.

Yours sincerely

Dr G E Berrios MA(Oxon), MD, FRCPsych, FBPsS
Chairman
Local Research Ethics Committee

Please reply to Box 148, Medical Advisory Office, Addenbrookes's Hospital

Huntingdon Health Authority
District Headquarters
Primrose Lane
Huntingdon
Cambs PE18 6SE
Tel: 0480 415120

Your ref: AGM/PA A86

21ST January 1994

Ms B Irvine
Macmillan tutor
Cambs. College of Health Studies
Education Centre
Hinchingbrooke Health Care NHS Trust

Dear Ms Irvine,

Re: Perceptions of Nursing Care in Hospices and Hospitals

This letter is to confirm that the above study was approved at the meeting of the Local Research Ethics Committee held on 18th January 1994.

The committee are required by their constitution to monitor all studies approved and would therefore appreciate a six-monthly progress and final report of the study.

Yours sincerely,

A. G. Meaking
Secretary
Huntingdon Local Research Ethics Committee

Forth Valley Health Board
33 Spittal Street
Stirling
FK8 1DX

Our ref: fd/hc(A)

13th September 1995

Ms Bridget Irvine
Lecturer in Palliative Care
Strathcarron Hospice
Randolph Hill
Denny
Stirlingshire
FK6 5HJ

Dear Ms Irvine

PERCEPTIONS OF NURSING CARE IN HOSPITALS AND HOSPICES

On behalf of the committee, may I thank you and Dr X for your attendance at the recent meeting and for you verbal presentation in support of the application papers previously submitted. I am pleased to confirm that the study has been granted ethical approval by the Forth Valley Ethics of Research Committee.

Approvals will stand in the first instance for a period of 3 years. Should the studies continue beyond that date you should return to the committee for an extension to the approval. You should similarly advise the committee of any alterations to the study design, seeking an amended approval in such circumstances. On completion of the study please advise the committee of any reference for publication of results.

Yours sincerely

F DRAPER
Acting Secretary
Ethics of Research Committee

Appendix III Information sheet for nurses

Study Title: Perceptions of Nursing Care in Hospices and Hospitals

RESEARCHER: BRIDGET IRVINE LECTURER IN PALLIATIVE CARE
STRATHCARRON HOSPICE
CONTACT NUMBER: 01324 826222

This leaflet is designed to give you further information about the study. Please consider participating in the project and do ask if you require any further explanation or you do not understand the information.

The purpose of the study is to find out your views about aspects of the nursing care that you are delivering.

There may be no direct benefits to the participants of the study but there may be changes in patient care and to the education of nurses following completion of the study.

Your participation will consist of two interviews to be held at different times. The interviews will each last approximately one-hour.

With your permission the first interview will be tape-recorded. You will be able to talk about aspects of the nursing care that you are delivering during these interviews. These tapes will only be listened to by my research supervisors and myself and will be destroyed at the end of the study. You can be assured of complete confidentiality.

The final report containing anonymous quotations will be available to all at the end of the study.

You may withdraw your consent and participation at any time without having to explain why.

Appendix IV Information sheet for patients

Study Title: Perceptions of Nursing Care in Hospices and Hospitals

RESEARCHER: BRIDGET IRVINE LECTURER IN PALLIATIVE CARE
STRATHCARRON HOSPICE
CONTACT NUMBER: 01324 826222

This leaflet is designed to give you further information about the study. Please consider participating in the project and do ask if you require any further explanation or you do not understand the information.

The purpose of the study is to find out your views about aspects of the nursing care that you are receiving.

There may be no direct benefits to the participants of the study but there may be changes in patient care and to the education of nurses following completion of the study.

Your participation will consist of two interviews to be held at different times. The interviews will each last approximately one-hour.

With your permission the first interview will be tape-recorded. You will be able to talk about aspects of the nursing care that you are receiving during these interviews. These tapes will only be listened to by my research supervisors and myself and will be destroyed at the end of the study. You can be assured of complete confidentiality.

These interviews will be in addition to your normal routine. You may withdraw your consent and participation at any time without having to explain why.

If you choose not to participate in the study your treatment and care will not be affected in any way.

Appendix V Consent form

CONSENT BY PATIENT OR NURSE (please delete) TO PARTICIPATE IN A RESEARCH PROJECT

I.....

Of.....

Hereby fully and freely consent to participate in the project entitled

Perceptions Of Nursing Care In Hospices And Hospitals

I understand and acknowledge that there will be no health risks to me resulting from my participation in the research. I also understand that I am free to withdraw my consent and terminate my participation at any time without penalty. I have been given the opportunity to ask whatever questions I desire and all such questions have been answered to my satisfaction.

I have received a written information sheet, a copy of which is attached to this form.

Signed.....

Witness to signature of patient/nurse (please delete) and to the fact that he/she has read the document and freely gives his/her consent.

Signed.....

(Witness must not be a member of the project team)

I confirm that I have explained to the patient/nurse the nature and effect of the project.

Signed.....

(Researcher)

Date.....Place.....

Appendix VI Prompt schedule- nurses

Prompt schedule- - In-Depth Interviews

Nurses

Can you start by telling me what you think effective or good palliative care is?

Can you think of an event where you were directly involved which you feel epitomised effective palliative care?

What was particularly significant about this incident?

Can you now think of the opposite of that, an incident, where you were directly involved which you feel, demonstrated ineffective palliative care for whatever reason?

What was particularly significant about this incident?

Can you describe to me the sort of person that you feel is a good palliative care nurse?

How do you think you meet your description of a 'good nurse' in palliative care?

Appendix VII Prompt schedule- patients

Prompt schedule- In-Depth Interviews

Patients

Can you take me back to the beginning of your illness and tell me what happened?

Can you tell me about an incident that has happened to you, as far as your care was concerned, that you felt was particularly good for whatever reason?

What was particularly significant about this incident?

Can you now think of the opposite of that, an incident, which you feel demonstrated ineffective care, for whatever reason?

What was particularly significant about this incident?

Can you describe to me the sort of person that you feel is a good nurse in palliative care?

Appendix VIII Blank grid form

A	B	C	D	E	F	G	H	I	J	K SELF AS I AM	L SELF AS I WANT TO BE

1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12. CARING	NOT CARING
13. SOMEONE I TRUST	SOMEONE I DON'T TRUST
14. SOMEONE I CAN TALK TO	SOMEONE I CAN'T TALK TO

Name: **Hospital/ Hospice** **Interview No.**

Appendix IX Contact summary sheet

Contact Summary Sheet

Name: **Interview number:**
Date: **Site:**

1. What were the main issues or themes that struck you in this interview?

2. Summarise the information obtained and not obtained on target questions for this interview

3. Note anything else that struck you as salient, interesting, illuminating or important in this interview.

4. What new questions would you add or how would you rephrase a question for the next interview

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Adapted from Miles and Huberman (1994) p.53

Appendix X Landfield classification for content analysis of grids

Landfield (1971) Classification for content analysis-

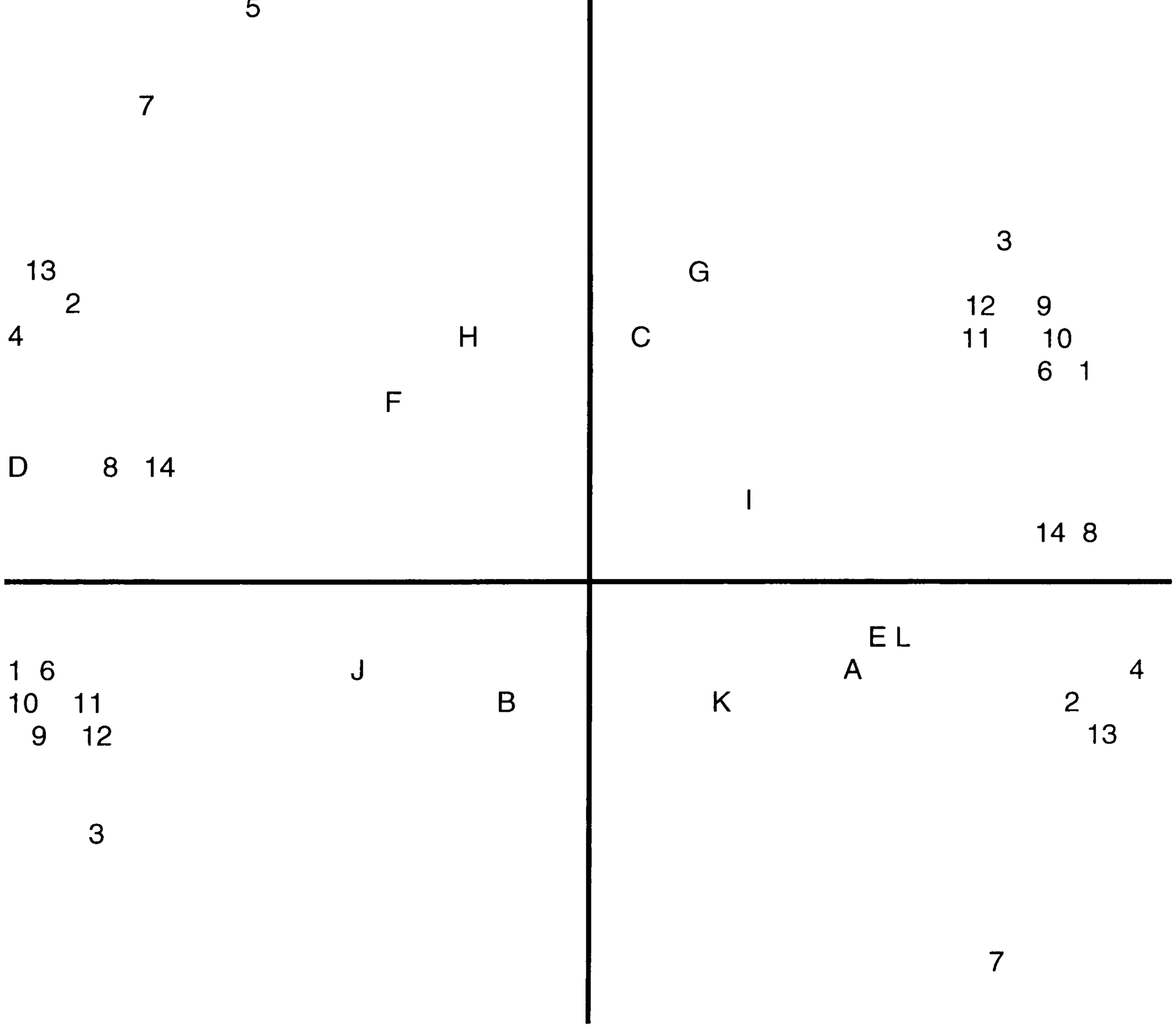
CONSTRUCT (N.B. POLE)	SCORE
1. **SOCIAL INTERACTION-** any statement in which face to face ongoing continuing interaction with others is clearly delineated	
2. **FORCEFULNESS-** any statement denoting energy, overt expressiveness, persistence, intensity or the opposite	
3. **ORGANISATION** -any statement denoting either the state or process of structuring, planning and organising or the opposite. The statement should indicate that a person either has or lacks a general trait of structuring, organising and planning ability or can be described as organised structured disorganised or unstructured	
4. **SELF SUFFICIENCY**-any statement denoting independence initiative confidence and ability to solve ones own problems or the opposite	
5. **STATUS-** any statement wherein references are made to either status striving or to high prestige status symbols or to a lack of status striving or to low prestige status symbols.	
6. **FACTUAL DESCRIPTION-** a characteristic so described that most observers could agree that it is factual. A fact would be a characteristic not open to question.	
7. **INTELLECTIVE-** any statement denoting intelligence or intellectual pursuits or the opposite.	
8. **SELF REFERENCE-** any statement in which the person taking the test refers directly to himself	
9. **IMAGINATION-** any statement denoting subjective activity which is supplemental to or divorced from reality or its opposite.	
10. **ALTERNATIVES** - open to alternatives or closed to alternatives the subject employs a- more than 1 description b- a qualified description suggesting the possibility of other descriptions c- a description suggesting a string openness or d- a description suggesting little receptivity to new alternatives.	
11. **SEXUAL-** any direct reference to sexual behaviour or implicit sexual behaviour	
12. **MORALITY-** any statement denoting religious or moral values.	
13. **EXTERNAL APPEARANCE-** any statement describing a persons appearance which may be either objective or more subjective.	
14. **EMOTIONAL AROUSAL-** any statement denoting a transient or chronic readiness to react with stronger feelings such as anger, anxiety disgust enthusiasm fearfulness grief joy nervousness surprise yearning e.t.c.	
15. **DIFFUSE GENERALISATION**	
16. **EGOISM-** any statement denoting self importance. High egoism may be either constructive or destructive and scoring will be more liberal- not debating whether e.g. the conceited person is really confident.	
17. **TENDERNESS-** any statement denoting susceptibility to softer feelings towards others such as love, compassion, gentleness, kindness, considerateness or the opposite.	
18. **TIME ORIENTATION-** past present or future- any statement denoting a state of mind which strongly implies an individuals future orientation and expectancy or a past orientation and expectancy. Some descriptions may imply both orientations and cannot be scored.	
19. **INVOLVEMENT-** any statement denoting a persistent effort towards that which an individual finds more generally and internally meaningful or restated a high or low internal and more total commitment or dedication to a strong pursuit of an interest occupation, way of life, philosophy or simply the state of commitment dedication or lack of such.	
20. **COMPARATIVES-**	
21. **EXTERNAL QUALIFIERS-** any adjective adverb or phrase which makes a description extreme or suggests a high degree of the characteristic	
22. **HUMOUR-** any statement specifically denoting either the ability or inability to perceive appreciate or express that which is funny, amusing or ludicrous	
TOTAL	

Appendix XI Repertory grid plot

Plot of Repertory grid

5 TUNNEL VISION
7 SEES BEYOND OUTER COVER
13 SOMEONE I DON' T TRUST
2 LACK OF COMMITMENT
4 SELF CENTRED
8 CARES JUST FOR SHOW
14 SOMEONE I CAN TALK TO

3 INTERESTED IN MY COMFORT
9 LACKS TOLERANCE
12 CARING
10 GENEROUS NATURE
11 UNDERSTANDING
6 NOT JUDGING
1 COMPASSIONATE



1 SUPERFICIAL
6 CRITICAL
11 IMPATIENT
10 UNGENEROUS
12 NOT CARING
9 TOLERATES IDIOSYNCRASIES
3 JUST INTERESTED IN JOB

14 SOMEONE I CAN TALK TO
8 GIVES SOMETHING OF SELF
4 UNSELFISH
2 COMES WHEN WANTED
13 SOMEONE I TRUST
7 APPEARANCES MATTER
5 TUNNEL VISION

Appendix XII Profile of informants

Profile of informants

INFORMANT	PROFILE	IN-DEPTH INTERVIEW	REP GRID	REASON
Interview 1 Jack Nurse Hospice A	Hospice Senior Staff Nurse with four years specialist palliative care experience.	✔	✔	
Interview 2 Bill Patient Hospice A	Hospice in-patient and day care patient with Motor Neurone disease	✔	✔	
Interview 3 Amanda Nurse Hospice A	Hospice Staff Nurse with two years specialist palliative care experience.	✔	✔	
Interview 4 Linda Nurse Hospice A	Hospice Staff Nurse with three years specialist palliative care experience	✔	✔	
Interview 5 Beth Nurse Hospice A	Hospice Staff Nurse with four years specialist palliative care experience	✔	✔	
Interview 6 Mary Nurse Hospice A	Hospice Staff Nurse with seven years specialist palliative care experience	✔	✔	
Interview 7 Sally Patient Hospice A	Hospice in-patient with advanced colorectal cancer	✔	x	Too ill
Interview 8 Sandra Nurse Hospice A	Hospice Staff Nurse with seven years specialist palliative care experience	✔	✔	
Interview 9 Toni Nurse Hospital B	Hospital Ward Sister on care of the elderly ward with an interest and undertaking a course in palliative care	✔	✔	
Interview 10 Lisa Nurse Hospice A	Hospice Ward Sister with five years specialist palliative care experience.	✔	✔	
Interview 11 Joe Patient Hospice A	Hospice in-patient with advanced lung cancer	✔	x	Died
Interview 12 Josie Patient Hospice A	Hospice day care patient with advanced breast cancer	✔	✔	
Interview 13 Hilary Patient Hospital B	Hospital in-patient on care of the elderly ward with chronic respiratory disease	✔	x	Refused
Interview 14 Elsbeth Patient Hospital B	Hospital in-patient on care of the elderly ward with advanced liver cancer	✔	x	Too ill
Interview 15 Jerry Patient Hospice A	Hospice day care patient with advanced prostate cancer	✔	✔	

Interview 16 Mark Patient Hospice A	Hospice day care patient with non Hodgkins lymphoma	✔	x	Too ill
Interview 17 Alan Patient Hospice A	Hospice day care patient with multiple sclerosis	✔	✔	
Interview 18 Liz Nurse Hospital B	Hospital Senior Staff Nurse on medical ward with an interest in palliative care and qualifications in palliative care	✔	✔	
Interview 19 Karen Patient Hospital B	Hospital in-patient on medical ward with chronic asthma	✔	x	Too ill
Interview 20 Rachel Nurse Hospital B	Hospital Staff Nurse on medical ward with an interest in palliative care	✔	✔	
Interview 21 Teresa Nurse Hospital B	Hospital Staff Nurse on medical ward with an interest in palliative care	✔	✔	
Interview 22 Sarah Nurse Hospital D	Hospital Clinical Nurse Specialist in breast cancer	✔	✔	
Interview 23 Tim Patient Hospital B	Hospital in-patient on medical ward with advanced colorectal cancer	✔	✔	
Interview 24 Alison Nurse Hospital D	Hospital Ward Sister on medical ward undertaking a course in cancer care and with a special interest in palliative care	✔	✔	
Interview 25 Nicola Nurse Hospital D	Hospital Staff Nurse on medical ward with a qualification in palliative care	✔	✔	
Interview 26 Jane Patient Hospital D	Hospital in-patient on medical ward in the terminal stages of leukaemia	✔	x	Died
Interview 27 Jason Nurse Hospital B	Hospital Charge Nurse on medical ward with a special interest in palliative care	✔	✔	
Interview 28 Kath Nurse Hospital D	Hospital Clinical Nurse Specialist in cancer/palliative care	✔	✔	
Interview 29 Lee Patient Hospital B	Hospital in-patient on medical ward with chronic asthma	✔	x	Too ill
Interview 30 Samantha Nurse Hospital D	Hospital Ward Sister on medical ward with community background and qualifications in palliative care	✔	✔	
Interview 31 Tom Patient Hospital B	Hospital in-patient on medical ward with advanced lung cancer	✔	x	Died
Interview 32 Glenda Patient Hospital D	Hospital in-patient on surgical ward with advanced colorectal cancer	✔	x	Too ill
Interview 33 Anne Patient Hospital D	Hospital in-patient on surgical ward with advanced breast cancer	✔	✔	
Interview 34 Geoff Patient Hospital D	Hospital in-patient on medical ward with advanced prostate cancer	✔	x	Died

Interview 35 Emily Patient Hospital B	Hospital in-patient on surgical ward with advanced breast cancer	✔	✔	
Interview 36 Gillian Nurse Hospital B	Hospital Ward Sister on surgical ward with an interest in palliative care	✔	✔	
Interview 37 Chris Nurse Hospice C	Hospice Home care sister with a palliative care qualification	✔	✔	
Interview 38 Emma Nurse Hospice C	Hospice Home care sister undertaking a course leading to a palliative care qualification	✔	✔	
Interview 39 Fiona Nurse Hospice C	Hospice Home care sister undertaking a course leading to a palliative care qualification	✔	✔	
Interview 40 Selina Patient Hospice C	Hospice in-patient with advanced breast cancer	✔	✔	
Interview 41 Jenny Nurse Hospice C	Hospice Ward Sister with a qualification in palliative care and general degree	✔	✔	
Interview 42 Brian Patient Hospice C	Hospice in-patient with advanced prostate cancer	✔	✔	
Interview 43 Mhari Patient Hospice C	Hospice in-patient with advanced breast cancer	✔	x	Died
Interview 44 Angus Patient Hospice C	Hospice in-patient with advanced prostate cancer	✔	x	Died